# Dynamics of attentiveness

Klaver, Klaartje

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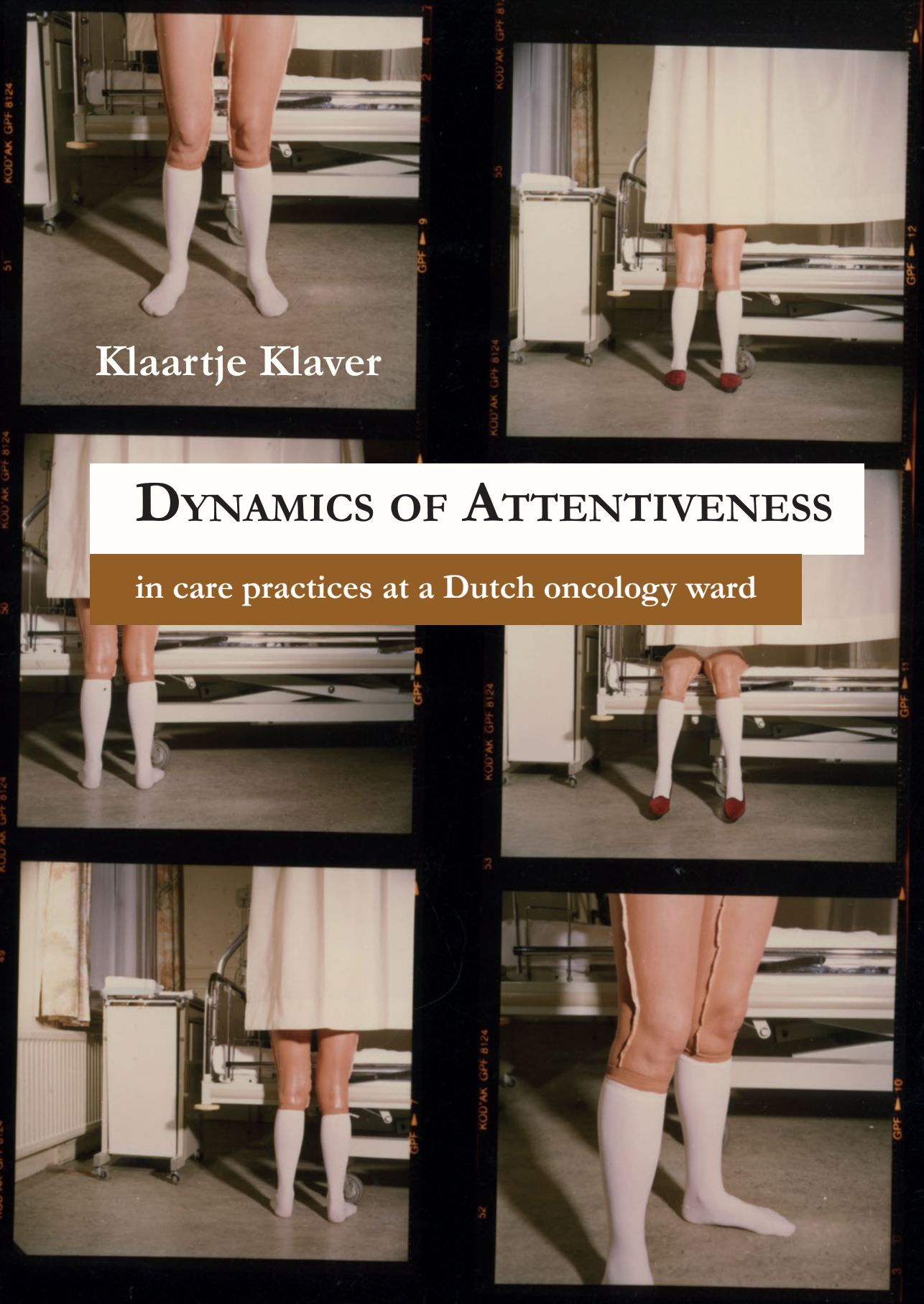

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## in care practices at a Dutch oncology ward

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Cover: Contactsheet of “Misprint” 1993 by Liza May Post
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## in care practices at a Dutch oncology ward

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Promotores:

Prof. dr. A.J. Baart
Prof. dr. J.E.J.M. van Heijst

Overige leden van de promotiecommissie:

Prof. dr. D.M.J. Delnoij
Prof. dr. P.J.C.M. Embregts
Prof. dr. B.M.G. van Engelen
Prof. dr. J.A. Roukema
Prof. dr. F.J.H. Vosman

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# Prologue

At the *Niet Normaal-manifestatie* in Amsterdam, I look at a work by photographer Liza May Post. The photo Misprint (1993) shows a young woman in a white hospital room. She stands with her back to us and we can only see her legs. Long white socks stretch up to her calves. The rest of her body is hidden behind a curtain. While I let this work sink in, I am overwhelmed by a feeling of sadness and loneliness.

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# Introduction

# 1

# INTRODUCTION

How can we understand attentiveness in care? What does it look like in actual care practices? Who is being attentive? What is the attentiveness focused on? What different types of attentiveness are there? Which factors do influence attentiveness? In this thesis, it is taken as given that attentiveness plays a crucial role in health care. This attentiveness - which we do not exactly know what it is - is the subject of this thesis. Attentiveness will be explored from various angles, and finally a descriptive and an explanatory model are constructed on the basis of empirical data that have been collected at the oncology department of a general hospital in the Netherlands. This thesis includes discussion of how attentiveness can be maintained and further stimulated in care. In order to be more specific about the objectives of the study, we now describe the environment in which these questions arise.

**A nice extra: attentiveness and care in prevailing views**

"For providing attentiveness, we need more hands at the bedside!" *(nurse)*
"Attentiveness? Well, that is the most important part of our job!" *(nurse)*
"More attentiveness in healthcare? Yes, sure, and in the meantime all they do is make cutbacks." *(physician in training)*
"We're quite well-off here when it comes to attentiveness around here: you're always allowed to get coffee or some ginger cake and they make you a sandwich anytime you want." *(patient)*
"So, you are doing a study on attentiveness? Well, you've got your work cut out for you here then." *(nurse specialist)*
"I often try to make time to be attentive." *(nurse)*
"I am quite happy about this doctor, he really gives our Mum attention. You can feel it." *(family member)*
"It is precisely that little bit of attentiveness I do it for." *(nurse practitioner)*
"It also depends on the way the patient experiences it; while some need attention and constantly like to talk about it, I myself am quite level-headed, I prefer to go without all the attentiveness and drama." *(patient)*

"To be honest with you, I am sometimes really deliberately trying to be attentive, but at other times I don't think of it all." *(physician in training)*
"If you have any tips on providing more attentiveness, I'll be happy to hear them." *(nurse)*
"I think it's great that you can dedicate these years to studying attentiveness in healthcare, especially in this time when it is all about money and efficiency." *(a friend)*
"Attention in healthcare? What do you mean by that exactly?" *(nurse)*

The remark from the nurse quoted last is the exception to the rule. Outside the world of science, I have rarely met anyone who asked what it was I meant exactly by attentiveness. On the contrary, people usually immediately gave me a reaction as soon as I told them about my research. Attentiveness in healthcare both seems to appeal to people's imagination and to speak for itself; everyone has something to say about it. This is not only the case when people talk about their experiences in healthcare amongst each other, but also in political discussions, in debates on the quality of healthcare and in scientific publications.

'They seem like little things, but a gesture, a compliment or a wink can make weekdays suddenly much nicer. This is because attentiveness - for each other, for your children, for your food, or the world around us - makes everything better. Attentiveness lies in the details. In a handy step so you can cook together with your child. Or in a beautiful tray on which you serve breakfast that you made with love' (IKEA 2015). IKEA goes for attentiveness. The 2015 guide is packed with the term. The wrapper of the Albert Heijn triple chocolate cookie also catches the eye: 'A treat for your appetite. Especially for you: with attentiveness and care'. Attentiveness appears to be a wonderfully fine term in many circumstances. When healthcare institutions advertise their care, they also often use the term attentiveness[1]. The Dutch hospital *Havenziekenhuis* advertises through movies with a famous actress using the slogan 'care with attentiveness'. Many healthcare organizations carry the word attention in their name[2]. Several small and large consultancies state that they are particularly concerned with attentiveness[3]. Attentiveness was also a theme picked up by professional associations in the area of care[4]. Furthermore, some health insurances picked the subject to advertise with[5]. The existing image of attentiveness seems to fit the needs of people who need care for themselves or a family member.

"Care is government responsibility, attentiveness is not", argues Moniek van Jaarsveld, director of an organization for the elderly, in Trouw (21 June 2011). She advocates for bringing

[1] *www.zorgmetaandacht.nl*
[2] E.g. the home care organization *Zorg & Aandacht B.V.*
[3] 'Carefulness', 'Aandacht in de zorg', and so on.
[4] See for example the leaflet *Attentiveness* of the V&VN.
[5] VGZ advertises with 'choose on the basis of attentiveness'.

care back to a basic package from which attentiveness can be cut; attentiveness is something that should be provided by the own social network of the person who needs care. Van Jaarsveld writes that family members and loved ones in today's society stay away legitimized when a family member needs care. Their lives are not equipped to care and their commitment is seen as "extra". Aside from the fact that this statement will evoke a sense of injustice and denial for people who do care for their loved ones with much love, this is indeed an alarming development. But what is concerning in the first place, is to consider attentiveness as an "extra", as Van Jaarsveld does. This implies that attentiveness is something one can give *beside* the real care.

"More personal attentiveness from the care workers", did Marjolein Herps read in the support plan of someone in an institution for people with disabilities (Markant, December 2015). She calls it jargon for 'more quality time with the professionals'. She explains it is included in the support plan for the employees to be reminded to give attention. They can also report about it in the plan: have I given enough attention to this person today, or has the early shift already been working on this goal? "Fortunately, there are quite easy solutions", Herps writes, "It is scheduled at what time there is some attentiveness. For example, five minutes daily, or maybe three times a week for half an hour." Herps is critical about the observation that things like attentiveness end up in support plans. But what strikes me even more, is that attentiveness is seen here as well as something apart from the real care.

This conception of attentiveness, as something you can give *beside* the real care, I also encountered in the hospital of my study. From the way doctors and nurses talk about it, it appears that attentiveness is often seen as belonging to the social aspects of care, and therewith contradicted to the medical-technical or nursing-technical side.

This dichotomy in thinking about care is also reflected in public discourses about care. Moreover, it appears there that this division is associated with thinking in terms of attractiveness. In the newspaper article "Job in healthcare is more than wiping snot" (Trouw January 6, 2010) one can read how a "care trailer" is used in attempts to inspire young people to choose for a job and training in care. Assuming that many young people find working in the care sector uninteresting because it is nothing more than "wiping snot", the emphasis in campaigns like this is on the technical aspects of care. This creates the impression that this is the only challenge of working in care: the technical aspects. Of course, it is understandable to work on a more positive image of working in health care, but it is striking that the technical aspects are emphasized. The assumption is that the technical aspects make care attractive, and as a result, the social aspect of care is negated. We must conclude that the social aspect of care - the human, warm, loving side -

is often neglected as core business of care. However, discourses in which that social side of care is exalted do also exist.

Likewise these different images associated with the dichotomy in thinking about health care, it is interesting to see how people think about the balance between the two sides described. As mentioned previously, the participants in my research share the opinion that care should in the first place be medically good, and second, it is considered important that caregivers are friendly. Several caregivers mention that a caregiver without giving attention can indeed be a good caregiver: 'A good doctor for sure. He just might be less kind to patients.' (a physician)

In the prevailing views on care, attentiveness is considered a category of friendly interaction, as (part of) the "social side" of care. In the prevailing opinion, care is better when given in a pleasant and friendly manner. At the same time, this social side, to which attentiveness belongs in these views, is considered a pleasant side effect; an extra that can make caring more beautiful. This perspective can also be found in the scientific literature on attentiveness and care. Studies on patient satisfaction and other studies on the experiences of patients show that patients find attentiveness a critical part of good care (Johansson et al 2002; Radwin 2000; McWilliam et al 2000, Paton et al 1999). In these studies, attentiveness is conceived as a category of communication or interaction. In order to be attentive, good social and communication skills are required (McQueen 2000).

In contrast to this view of attentiveness as an additional social part of care, this study departs from a wider view on attention. This is a direct result of the use of a broader vision on care: care is perceived as more than only competent and communicative. What is good care?

> Based on research in China on how elderly die in Shanghai, on my career-long interest in the failure of caregiving in medicine, and especially on my experience as the primary caregiver for my wife, Joan Kleinman, who suffers from Alzheimer's Disease, I have come to understand caregiving as an embodied experience of 'presence'. By this I mean the quality of being there for and with a loved one in the fullness of one's humanness - alert, engaged, responsive, resonant, supportive - as a foundational existential act of protecting, assisting, emotionally supporting and morally sustaining the other and one's relationship with him or her as the grand arc of a life bends inevitably toward diminution and death. [...] But even in the absence of detailed studies, we can see that constituting and sustaining presence in professional settings is by definition extraordinarily hard to achieve. Hence, how can it be surprising that professional caregiving by doctors and nurses seems to be characterized by the absence of 'presence'? It is impressive when we

> see busy and distracted professionals find a way of being there for their patients (Kleinman 2009: 97).

This thought could be seen as the starting point of this research. Psychiatrist and cultural anthropologist Arthur Kleinman emphasizes the importance of relatedness for care. At the same time, he argues that relatedness is put under pressure in the current professional organization of care.

**Attentiveness in ethics-of-care perspective**

Attentiveness is a concept with many meanings. It is for that reason that books on this theme often start with emphasizing the versatility of the phenomenon. Baart (2004) calls his essay on attentiveness "a kaleidoscopic argument" (2005: 14), Burggraaff writes about "a concept with flip-edges" (2002: 25), Van Hoorn (2007) understands attentiveness as a diamond from which she highlights the different facets, and the introduction of Van der Kolk's (2010) book on attentiveness is entitled "Attentiveness is of everything".

Attentiveness, or attention, is most often defined as the behavioural and cognitive process of selectively concentrating on a discrete aspect of information, while ignoring other perceivable information (Anderson 2004: 519). Attentiveness is compared to a spotlight shining on a dark background and illuminating some aspects of the existing world waiting there to be "discovered". Attention in this meaning remains a major area of investigation within education, psychology, neuroscience, cognitive neuroscience, and neuropsychology. However, it is only a part of the picture. Following Gurwitsch, Arvidson (2006) advocates for an analysis of context in the study of attentiveness. Arvidson indicates that stimuli, even when *unattended stimuli*, obviously are nevertheless presented: unselected areas are actually seen. As Waldenfels put it: "One *sees* always more than one *looks at*, and one *hears* always more than one *listens to*" (Waldenfels 2008: 7).

This broadening of the concept is relevant to the study of attentiveness in hospital care, because there, in addition to performing tasks and achieve goals, it is often important to notice something without being focused on it. Sometimes it is important for doctors and nurses to concentrate their attention on something without becoming disturbed, but at other times they must be open to distraction, for instance when something else needs more attention. It is not always clear in advance what the attentiveness should be focused on. The context is not a passive factor waiting until someone draws his attention to it; it is a dynamic and active factor from which stimuli may arise. The point is to consider the relationship between the dynamic context

and focused attentiveness. Waldenfels (2004) explains it as follows: attention is the interaction between something happening to me (*es fällt mir auf*) and something I do (*ich merke auf*).

This study uses an ethics-of-care perspective. The ethics of care is a political and ethical approach that understands care from a particular viewpoint. Relatedness plays a crucial role, as persons are understood to have varying degrees of dependence and interdependence on one another. This is in contrast to deontological and consequentialist theories that tend to view persons as having independent interests and interactions. The following four features are necessary to speak of an ethics of care: a) relationship based programming, b) recognition of situatedness and contextuality and therefore judgments are not generalizable (particularity), c) care ethics is a political ethical discipline, and d) the theory is empirically grounded or at least informed (Klaver, Elst, Baart 2014). In her book on professional loving care, which uses a care ethical perspective, Van Heijst (2011) argues that the main purpose of care is not repair of the patient's body or mind, but the care-receivers' experience of being supported and not left on their own.

Attentiveness plays an important role in the ethics of care. It is defined as the quality of individuals to open themselves for the needs of others (Tronto 2003). Attentiveness meaning the noting of the existence of a need by assuming the position of another person, is seen as the first step to care, which should be followed by a responsibility to respond to this need. Care ethicists have emphasized the meaning of attentiveness for recognition (Baart 2004, Conradi 2003). Attentiveness does not only have an instrumental function, but it can be understood as an expressionate act (Van Heijst 2011): by being attentive to someone, it is shown that you care about him. Thereby, a relationship can be formed between a caregiver and a care receiver that is broader than functional; a relationship in which good care can be given. This is care that is experienced as care, care from which the receiver benefits, care that is more than repairing defects. In a book about nursing, Baart & Grypdonck (2008) describe how attentiveness can have a socially enclosing meaning. Attentiveness can enclose another person in a relationship.

This socially enclosing aspect of attention is not a new idea, but has been developed by a number of philosophers, including Buber (1970). Arvidson (2006) uses the work of Buber when explaining what happens when attention becomes focused on some*one* rather than some*thing*. He calls this "moral attention", by which he means that another person has some special relevance to the subject. This does not mean a practical or emotional relevance, in the sense that someone e.g. uses another, or appreciates or pities him, or is fascinated by him; these are relevancies that fail when it comes to moral attention. In moral attention the relevance between the *theme* of the attention and the *context* must be such that the other becomes the theme within the context of the

ongoing attentive life of the subject. This is what we mean when we say that another person matters to you: 'You are directly relevant to me'. This "compassion" - literally "standing together" - is a special principle of relevance for attention.

In his book *I and Thou* (1970) Buber was not directly concerned with attentiveness, but his famous distinction between the *I-You* encounter and the *I-It* relationship may constitute a starting point to describe the moral nature of attention. According to Buber, a person may be presented thematically as a thing, as an *It* in an *I-It* relationship. Or a person can be presented as a being, as a *You* in an *I-You* relationship. What exactly is the difference? In his *Meditations*, Descartes wrote that "the people I see walking may be robots, since all I really see are coats and hats and boots" (1981: 155). But when we recognize that there are other people in the world and that there are similarities and common ground between us, what will then be presented when we are attentive to another person? Buber (1970) saw most encounters between people as *I-It* encounters, since they relate to the practices in which the encounters take place. For example, you go to the bakery and buy bread. According to Buber, the uniqueness of the *I-You* encounter is the blurring of the surrounding environment and the practical interests. Attention is paid to the person as a whole, while the surrounding world blurs. It is as if the person suddenly becomes three-dimensional and the context flat. The surrounding world as a practical world is replaced by a moral world. Now it does not matter if you have blonde hair or brown hair or no hair. Whether you are healthy, have AIDS, or cancer. It is all still presented, but only marginally. Such facts "are irrelevant to *You* as theme" (Arvidson 2006: 152). "This attentiveness does not see an albino, but it sees Jelle that has albinism and loves football", Baart writes (2004: 82 [my translation, KK]).

The selection of qualities such as hair color or disease obstructs being morally attentive. As Buber writes: "Even as a melody is not composed of tones, nor a verse of words, nor a statue of lines - one must pull and tear to turn a unity into a multiplicity - so it is with the human being to whom I say *You*. I can abstract from him the colour of his hair or the colour of his speech or the colour of his graciousness; I have to do this again and again; but immediately he is no longer *You*" (1970: 59 in Arvidson 2006). Only by looking further, by looking openly, our attentiveness may have a beneficial effect: someone finds me special enough to turn toward me. Baart writes: "Attentiveness melts down grief, makes contact with its lonely carrier, pulls it gently out of his place, and stores it again: this time not in pain but in a relationship" (2005: 83).

Despite its importance, it has hardly been examined what attentiveness is in professional health care practice, and how it is influenced and reworked by culture and other social realities in particular local contexts. This thesis seeks to understand attentiveness in care empirically and theoretically, without fixing its meaning. The examples and explanations attempt to encircle the

meaning of attentiveness, but also leave space for what emerges 'between the lines'. The study aims at providing starting points for analyzing attentiveness in care. It studies doctors' and nurses' attentiveness at the oncology department of a general hospital.

**Objectives & Outline of the thesis**

The objectives of the current study can now be formulated. The first objective is to explore how we can understand caregivers' attentiveness in the hospital oncology practice. Chapters 2-5 of this thesis form a description of the construction of a grounded theory[6] of attentiveness in care practices. In order to obtain sensitizing concepts, the existing literature on attentiveness is inspected and made usable for the empirical study on the subject. Then the empirical study is explained and the descriptive findings are presented. Participant observation and informal conversations on the oncology department of a general hospital form the basis of this study. The reflection on the integration of an empirical study with an ethics-of-care perspective plays a central role in these chapters. After this broad empirical-ethical exploration of attentiveness in care, the focus of the study is shifted. The second objective of this thesis is to explore how attentiveness can be stimulated and maintained in order to contribute to good care. This objective asks for an explanation of the occurrence of different types of attentiveness, which will be dealt with in chapter 6 and 7. These chapters also reflect on what cannot be found or explained.

Chapter 2 of this thesis provides the theoretical background from which the study is undertaken. A discussion of the existing literature on attentiveness from various disciplines provides the sensitizing concepts required to enter the study field. The existing literature on care provides no unanimous definition of attentiveness. In order to examine the functioning and aspects of attention, we need a comprehensive clarification of the concept: how is attentiveness understood in this study? This empirical study has an exploratory nature. This means that we do not yet know what attentiveness is and how it works in the hospital - this is precisely one of the research questions. Yet, to examine attentiveness in actual care practices, we do have to sensitize ourselves for the phenomenon in order to avoid overlooking relevant things. In this chapter, we present a for this study relevant conceptualization of attentiveness. This is a care ethical conceptualization that is inspired by insights from other disciplines.

Chapter 3 examines how our use of an ethics-of-care perspective interacts with our interpretative qualitative study. It includes a first 'unveiling' of the empirical observations.

[6] Glaser & Strauss 1967

'Habitus' comes to the fore as a fruitful research instrument, and attention is shown to be part of the core business of medicine. However, attentiveness has many facets, and not all of these are equally present in hospital care. It becomes clear that attentiveness can only have its good meaning and effect if it is the right kind given at the right time. Caregivers frequently succeed in showing the proper attention, yet this is often done tacitly: attentiveness is not an easily accessible subject matter, and caregivers do not always use the term 'attentiveness.'

Chapter 4 zooms in on the use of an ethics-of-care perspective while using an intradisciplinary framework. Since lending from and mixing varying disciplines and backgrounds carries the risk of losing the heart of the matter, we discuss what is needed to retain a distinct care ethical discipline. This is done by presenting four essential criteria that should sharpen our care ethical focus, and in further developing an ethics of care as a discipline. Finally, we present two intradisciplinary attempts that keep the care ethical identity upright.

Chapter 5 presents a descriptive model of attentiveness in practice. The development of a descriptive model precedes and enables the method of constant comparison as part of the grounded theory approach. Furthermore, as the descriptive model comprises the components of attentiveness, it provides caregivers with opportunities to analyze care situations from the perspective of attentiveness and reflect on them.

Chapter 6 presents the grounded theory of attentiveness that arose from this study. It shows that two factors are decisive when it comes to explaining the occurrence of the different types of attentiveness. The first factor refers to the question whether the attentiveness is person-oriented or task-oriented: e.g. is the caregiver's attention focused on the cancer or on the person who has cancer? The second factor concerns the role of attention for care in the view of the caregiver. This appears to vary from attentiveness making care possible to attentiveness making care impossible. The significance of socio-institutional enclosure is also explained, as this emerged as a key concept within the findings.

During the analysis, we have found that, although we can understand and explain many things, it seems that attentiveness always escapes the analysis partly. This observation, the inexplicabilities coming forward in the analysis, is the reason for chapter 7. We propose that this inexplicable nature is not only an unavoidable element in the analysis, but also an indispensable ingredient of good attentiveness - and therefore, there should be space for it in healthcare.

Chapter 8 reflects on the main findings of this research in relation to the objectives outlined in the introduction: gaining a better understanding of attentiveness in the hospital oncology practice, and finding starting points for exploring how attentiveness as we see it can be

stimulated and maintained in order to contribute to good care. Several methodological issues of this study are considered as well.

The chapters of this thesis are interspersed with four interludes. The first three interludes are background stories consisting of descriptions of the daily business of caregivers in the hospital. Three working days of care professionals are described: a working day of a nurse on the ward, a working day of a resident doctor, and a working day of an oncologist. The three days are composed of different observation days, so the care professionals in the three stories do not reflect three real care professionals. The background stories are meant to draw a picture of the research setting and to give the reader an idea of the daily work of the different care professionals that participated in this study. Several differences come to the fore, not only in the occupational groups (specialists, doctors, nurses) and between their positions in the hospital, but in particular, when it comes to moments of socio-institutional enclosure. The descriptions speak for themselves and further interpretation or conclusions are therefore omitted. The fourth interlude presents one case of attentiveness as a whole. As this thesis leaves little room for the presentation of complete case descriptions, this interlude is meant to show an integral case description and how it, through the process of analysis, ended up in and informed the grounded theory.

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# ATTENTIVENESS IN CARE

## Towards a theoretical framework

Klaver, K. & Baart, A. 2011 *Nursing Ethics*; 18(5): 686-693

**Abstract**

The purpose of this article is to shape a theoretical framework of attentiveness in care, which may function as a background to study attentiveness in a health care setting empirically. More insight into the functions, forms, and aspects of attentiveness in a particular health care setting is important, as there is a lack of indicators and criteria that enable a sharp picture of the caring side of health provision. The concept of attentiveness and its relation to care have seldom been examined thoroughly and broadly. This article argues that attentiveness is constitutive for good care, as it can create a space in which a relationship may arise.

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# ATTENTIVENESS IN CARE

## Towards a theoretical framework

### Introduction

In regular considerations of quality of care there is a lack of indicators and criteria that enable a sharp picture of the caring side of health provision. Such indicators often remain hidden in contemporary approaches to quality of care but nevertheless seem to be highly relevant from the perspective of patients.[1] Insight into the functions, forms, and aspects of attentiveness in health care may reduce this problem. What exactly is attentiveness? A quick Google search on 'attentive care' offers us many care providers, services, and institutions, claiming that it is them we need when looking for attentive care. The idea of attentiveness shows to be appealing to people who need care for themselves or a family member. It seems to fit with their feelings and thoughts at the moment they have to hand over care to professionals. However, despite this common ground, there has been little discussion about the typical character of attentiveness, and its effects or consequences. This article attempts to formulate a theoretical framework of attentiveness in care, which may function as a background for an empirical study that is qualitative in nature. In the first section, a perspective on care is sketched. In the second and third section we elaborate on the concept of attentiveness and how it is connected to care, and finally, we argue for an integration of the notion of structural context in the theoretical framework.

### A perspective on care

For the development of an understanding of (good) care, this article builds mainly on theoretical perspectives from the ethics of care. The ethics of care is a political-ethical approach that tries to understand care by looking at it in a particular way. It is a cluster of normative ethical theories that were developed by feminists in the second half of the twentieth century. The idea of an ethics of care arose with the publication of Gilligan's *In a Different Voice* and has been developed and applied in a number of ways.[2-6] Ethics of care emphasizes the importance of relationships. It is based on the principle that there is something 'good' in every form of care. That good is more

than useful, efficient or pleasant. It is morally by nature: it aims at a good life, with and for others, in fair institutions and a decent society. Our approach also draws from the way in which philosophers Ricoeur[7], Tronto[8], Sevenhuijsen[9], and Conradi[10] have developed this perspective. These authors promote care as a political value as well as one that concerns interdependencies between people in their private lives. Particularly Sevenhuijsen has argued that social policies should be based in an ethic of care and has developed an analysis to interrogate social policies from this perspective.

Following these works, two Dutch authors have further developed the ethics of care especially regarding professional (health) care. Van Heijst[11,12] shows that an ethic of care looks at care with a special interest for (a) the uniqueness of specific situations, (b) the fact that care relationships always bring dependence and asymmetry with them, (c) the fact that people are vulnerable because of their corporality and (d) the importance of building a relationship with people who are depending on care, to find out what is good for him or her. In her work good care is called 'professional loving care'. With that Van Heijst means professional health care in which caregivers (and institutions) concern themselves with ordinary, humane compassion. She argues that care is a human relation, since it anticipates someone's neediness or dependence. She calls it professionalism based on charity. Van Heijst is in this way opposing the dominant view in which care is no more than providing service in a market-oriented, commercial and effective way, and she argues for another discourse to think about care. Two additions should be made here. Firstly, the word 'love' in the context of care (professional loving care) evokes varying reactions. One may associate it with charity, faith, Christianity, and piety, and therefore it seems to radiate an obnoxious (or attracting) value. However, we emphasize that in our view good care is not regarded as based on whichever religious belief. Secondly, professional loving care is explicitly not the opposite of good medicine. Van Heijst sets out that competent, technical, medical care is extremely important, but only in the understanding that caregivers realise that reparation of problems, relief of pain, or curing diseases is never a goal in itself. The overall goal of every form of caregiving is to stand by someone who is in pain or misery. Van Heijst puts forward that professionalism and loving care should never be disconnected, simply because care is about people working for and with people. Additionally, professional loving care does not only concern itself with the attitude of individual caregivers. To structurally guarantee professional loving care, it is also needed to adapt the system of care.

Baart[13,14] has developed the presence-oriented approach to give shape to good care. This perspective helps to see how professional loving care may be put in practice. With practicing 'presence' Baart means that caregivers try in every possible way (as for tempo, goals, work

rhythm, language, work style, interest, perspective, etc.) to attune with the care receivers themselves. Practitioners of presence do not distance themselves when something seems to be insolvable or incurable as they are not only directed by the desire to successfully fix what is broken, or to only cure. Their first and foremost aim is to learn to know the other in a meaningful relationship, through which he or she will come to dignity. The practitioner of presence offers, in addition to (professional) knowledge and experience, him- or herself. Baart explains that this happens transparently, and that it starts from a passive mode. In the end however, it is - just like 'professional loving care' - a practical way of doing that requires competence, and in which loving care and professionalism go hand in hand.

In our perspective, care is the effort to keep life going when it is failing, and when it loses quality and autonomy. It is given before, during and after the endangerment of the continuity, and is more than putting things right after they have been disturbed. Although care implies a specific attitude, intention, readiness, and concern, it is not that by itself. Care must be fine-tuned to the specific needs of the care receiver, as these reveal by the caring relation. It needs the care receiver's experience to know for sure that it is care and nothing else (such as meddlesomeness or self-centred interventions on the part of the so-called caregiver).

**Attentiveness**

This article further elaborates on the concept of attentiveness. The importance of attentiveness in the context of care might seem obvious; however, there is no clear definition of the concept as it is used in various ways. This paper will explore the uses of the term and then suggest a tentative conceptualization. Qualitative research should be used to understand attentive care in practice.

In common parlance the word attentiveness has several slightly different meanings. Being attentive can mean 'giving care' or 'being watchful', and someone who is attentive may be offering devoted and assiduous attention to the pleasure or comfort of others. An attentive person may also be expressing affectionate interest through close observation and gallant gestures (which even might become overdone, e.g. 'playing the attentive suitor, complete with roses and bonbons'). When looking at the noun 'attention' instead of 'attentiveness', the meanings are even more varied. Attention may be the concentration of the cognitive powers upon an object (closely listening or observing), or the ability or power to concentrate mentally. It may also mean consideration or courtesy, and when military personnel are standing erect and motionless during drill or review it is called 'the troops stand at attention'. Likewise these various meanings, there are several synonyms of attentiveness that lift up different aspects of attentiveness, such as

awareness, alertness, watchfulness and vigilance (being attentive understood as the trait of being able to notice what needs attention), concentration, diligence, focus and heed (being attentive understood as the trait of not being distracted from what needs attention), thoughtfulness, deliberation and consideration (the aspects of thought in being attentive), and concern, solicitude, respect, devotion, application and sympathy (attentiveness hiding feelings or affection).

Similar to differences in the use of the word, both attention and attentiveness are also studied in different ways. In the psychological literature, attention is understood as the cognitive process of selectively concentrating on one aspect of the environment while ignoring other things. Focalization and concentration of consciousness are of its essence. Examples include listening carefully to what someone is saying while ignoring other conversations in the room, or listening to a cell phone conversation while driving a car.[15,16] What can be learnt from psychological literature is that attention is involved in the selective directedness of our mental lives. The nature of this selectivity is one of the principal points of disagreement between the extant theories of attention. The instances of attention differ along several dimensions of variations: in some examples attention is a perceptual phenomenon, in others it is a phenomenon related to action. Besides, theorists discuss whether the selectivity of attention is voluntary, or rather driven independently of the subject's volition. The difficulty of giving a unified theory of attention makes this a topic of philosophical interest as well.[17] Attention is furthermore of philosophical interest because of its apparent relations to a number of other philosophically puzzling phenomena. There are views suggesting that attention is closely related to consciousness. It is controversial, however, whether the relationship of consciousness to attention is one of necessity, or sufficiency. For example, there is a good reason to think attention is necessary for conscious experience, however there is equally good reason for thinking that such attention is not sufficient. The reason is simple: we sometimes perceive things in the absence of conscious experience. There are also perspectives linking attention to demonstrative reference (where one speaks or thinks about an object visible in one's vicinity; the ability to conceive of it and oneself), to the development of an understanding of other minds, and to the exercise of the will.[18] In addition to assessing the most recent laboratory results from prominent psychologists, cognitive scientists, and neuro-scientists, many philosophical works on attention are based on the work of phenomenologists such as Gurwitsch, Husserl, Merleau-Ponty, and Sartre.[19,20]

Beside psychological and philosophical literature, there is an extensive amount of spiritual works on attention. In spiritual literature, attention or attentiveness is understood as a necessary way of doing or being if we are to know (or to help) other people (or things). In this way a notion of attention seeks to unite contemplation and action. According to Murdoch attention is an

imaginative and normative use of moral vision that burns away the selfishness of natural human desire, leaving behind the purified desire of just and compassionate love.[21] In literature of a spiritual nature, attentiveness is a way of being or doing (sometimes even regarded as a 'lifestyle'), which takes shape in various spiritual or religious traditions. Attentiveness is an important concept in for instance mindfulness, which is a Buddhist concept that is now broadly conceptualized as a kind of nonelaborative, nonjudgmental, present-centered awareness in which each thought, feeling or sensation that arises in the attentional field is acknowledged and accepted as it is. Attentiveness is also an important concept in for instance the Benedictine spirituality (that says: whatever you do, do it with attention).[22] The importance of such spiritual notions for our conceptualization of attentiveness lies especially in the aspect of openly observing. Attentiveness might be seen as wondering, which is described as a way of learning to know beyond the obvious understanding.[23] When wondering, people break through established patterns of observing, naming, thinking and handling. In other words: it is not about placing someone, but about aiming to learn to know slowly and openly.

**Attentiveness in care**

Attentiveness is not simply a term related to psychological, philosophical or spiritual theories; it is an interdisciplinary concept. When looking at care, attentiveness is a complicated but essential part that involves an ethical aspect. In the care ethics tradition, attentiveness is described by Tronto in her book *Moral Boundaries*.[8] Tronto analyses care and describes four[7] phases, which are conceptually separate, but interconnected in practice. She firstly mentions *caring about*, which involves the recognition that care is necessary. It means noting the existence of a need and making an assessment that this need should be met. Often it will involve assuming the position of another person or group to recognize the need. The next phase in the caring process is *taking care of*, which means assuming some responsibility for the identified need and determining how to respond to it. It also means involvement in organisational activities. Thirdly, Tronto describes *care-giving*, as the direct meeting of needs for care. This involves physical work, and almost always requires that care givers come into contact with the objects of care. Tronto's fourth phase is *care-receiving*: this final phase recognizes that the object of care will respond to the care it receives; the patient feels better. What was meant to be good care, should be experienced as such. Tronto includes this phase as it provides the only way to know that caring needs have actually been met:

[7] In 2013, Tronto added a fifth phase (Tronto J. *Caring Democracy. Markets, equality, and justice.* New York: University Press, 2013).

sometimes it is hard to identify the need for care, and in this phase one can check whether it has been done adequately. And even when the perception of the need is correct, how to choose to meet the need can cause new problems. Tronto couples these four phases with four ethical elements of care, namely attentiveness, responsibility, competence, and responsiveness.

As becomes clear, attentiveness is described by Tronto as the quality of individuals to open themselves for the needs of others. Attentiveness meaning the noting of the existence of a need by assuming the position of another person, is by Tronto seen as the first step to care, which should be followed by a responsibility to respond to this need. This is an important but too narrow view. We argue for a broader view, in which attentiveness is not only the first step in care, but also a good in itself. Attentiveness makes people flourish, it makes them do well. Even without taking the responsibility and undertaking action, attentiveness may have a beneficent meaning. Baart[24] goes more deeply into attentiveness, and argues that it may be seen as a socially including practice. He shows that it has a double character and (analytically) distinguishes instrumental attentiveness (that dominates contemporary healthcare) from beneficent attentiveness. Instrumental attentiveness may for example be the attentive listening of a doctor to a patient with the purpose of diagnosing as good as possible. Beneficent attentiveness does not have such an instrumental purpose; it is simply attentiveness for the sake of attentiveness.

Attentiveness understood in this beneficent way is a helpful but also tricky phenomenon. By disconnecting attentiveness from a functional purpose, attentiveness in a violent meaning comes to the fore. Besides a beneficent meaning attentiveness can also have a totally different character: it might for example take the shape of discipline or control (e.g. by governments, insurance companies) or it may appear in the form of stalking (e.g. by 'loverboys'). In our conceptualization, we focus on the beneficent meaning of attentiveness, but the violent meaning of attentiveness will not be forgotten. Therefore, this article argues for an understanding of attentiveness as a practice that can, from two sides, create a space (that is bigger than functionality) in which a relationship may arise. When attentiveness is understood as creating such an intersubjective space, the focus is not on either the caregiver or the carereceiver, but the emphasis is on the relation.

**Attentiveness: care in context**

Contemporary health care in the Netherlands (and elsewhere) is complicated. It has become a complex whole, and pressure is put on it from many sides. There is pressure from education and trainings (new approaches, protocols, and techniques), but also from the bureaucracy

(registration, production), and from the current market-oriented thinking and jargon. As has become clear, care ethicists like to think about care differently from those who see it from a market oriented and suchlike perspectives. They see care as solicitude: solicitude for people who are not feeling well, and in that light it is worked out how care and attentiveness are internally connected. However, the currents of contemporary health care may not be ignored. It is inescapable to face the structural context in which care takes place, and the possible ways it is intervening with the connection of care and attentiveness. In this article it is explored how attentiveness and care are connected on a conceptual level, but a supplementary understanding of attentiveness in a particular health care context is needed.

The literature on ethics of care regularly mentions the importance of context, beginning with the work of Tronto, which strongly emphasizes the influence of political context. However, the particular ways in which these context factors influence care practices are underinvestigated: the context may be presented formally but is not meaningfully integrated with an analysis of action. The ethics of care largely focus on agency through such theories as phenomenology and hermeneutics, and resultantly, social structure may be erased or seen as epiphenomena of agency. This failure to acknowledge the importance in theory of social structure can produce a very one-sided perspective on the experience of patients and health professionals. In this section attention is paid to the concept of social structure and how this may help us to understand how patients and health care professionals live and experience clinical practice.

The use of the term social structure is perhaps traditional in that it analyses broad, even global processes, but we wish to argue that social structure is also important in examining the micro world of social interaction. For example, the interaction between a nurse and a patient makes little sense without an understanding of the structural location of the 'nurse' and the 'patient'. This location influences (if not determines) some of the ways in which that interaction takes place, which is in turn influenced by broader social, cultural, economic, and historical factors[8]. The power of a structural approach comes from its basic premise that people's attributes, attitudes and behaviour arises from their position in the social structure; and further, that particular structural arrangements – the way things are organized – will differ in their social effects.[25] In other words, the test of a structuralist explanation is whether or not the actual people in a certain situation were removed and replaced with others would they act in similar ways. However, although the aim is to give attention to structure, we do not want to erase agency. Strictly structural approaches have their limitations as well, and the central problem is that too often these theories do tend to underplay the role of human interaction. If the person and the

[8] See also Chapter 6 for a description of how this works in practice.

small group are expected to act as an explanatory tool for more or less all explanations about the social world in theories based on agency, for structuralists the human being seems to disappear altogether.

Giddens[26] is one of the theorists on social structure and his theory is attractive because it attempts to overcome the division between structuralist/functionalist approaches and the hermeneutic/interpretative tradition. Giddens' structuration theory proposes that agency and structure are essentially intermingled into a duality rather than a dualism. Therefore, the two concepts are indistinguishable from each other. Social structures enable *and* constrain, as opposed to structuralist explanations where the overwhelming sense is that human beings are simply products or puppets of structural relationships.[25] Individuals are never totally defined by social structure but are constantly reflecting on their circumstances and while their interactions may be constrained by those social structures they are not determined by them. They even reproduce those structures by their acting: that reproduction is at the same time a change and reinventing of the structure. We think this is certainly an improvement on the interactionist erasure of social structure, and Giddens provides useful insights into how people have to work within the constraints of social structures while not removing their agency. His theory is an example of central conflation where agency and structure collapse in the middle and so it becomes impossible to distinguish one from the other. This mutual relation between structure and agency is essential to the approach of Institutional Ethnography.[27,28] This method of inquiry understands social life to be constituted in the actions of embodied people going about their everyday lives. It examines how people are socially organised to accomplish their day to day existence, and how the routine features of social life are thereby established and maintained. In this way, the research can be relevant to patients *and* clinicians, to families *and* managers, as is also shown in the approach of Hospital Ethnography, as developed by medical anthropologists and sociologists.[29,30]

The ideas of structure and agency give shape to our theoretical framework that finds itself somewhere between the disciplines of social science and ethics. We are not as many social scientists putting forward that what people know as their social existence is largely determined by the overall structure of society, nor are we arguing for a more ethical presupposition by stressing the capacity of individual agents to act freely. In other words: we take seriously the inner perspective of the actor, with some kind of freedom, but in addition to this we stress the effect of structural context factors. We prefer to be in the middle of these disciplines by trying to find a balance between the two positions.

## Conclusion: to an empirical study

In what ways is this article valuable for empirically researching attentiveness in a health care setting? This text offers a theoretical framework and emphasizes three themes that stand out as major issues in our thinking on attentiveness in care. Firstly, the importance of relations is emphasized. This means that an empirical study of attentiveness in a health care setting should look at establishing relationships. Secondly, we stress the importance of attentiveness as a practice that can create a space in which a relationship may arise. Attentiveness may have an instrumental function, which dominates in contemporary health care, but attentiveness may have a beneficent meaning in itself as well. Thirdly, it is important to pay attention to the structural context in which practices take place. This means that one should consider and search for the possible ways in which the context of the hospital influences the crystallisation of attentiveness in practice. With regard to a hospital it is expected that many factors of varying types play a role, however, four are mentioned here: institutional or systemic pressure (involving issues such as the space of the hospital, the way certain things are organised or financed, how patients are referred, protocols, rules, etc.), disciplinary pressure (the specific perceptions and assumptions that go with the disciplines of for instance doctors, or nurses[31]), the oppressive influence of professionalism (what is to be regarded as professional) and discourse (different ideas and views of care, for example a 'market discourse').

The theoretical perspective on attentiveness as set forth in this article argues that a qualitative empirical study should take into account these three issues to get more insight into the crystallization of attentiveness in a particular health care context.

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3

# DEMARCATION OF THE ETHICS OF CARE AS A DISCIPLINE

## Discussion article

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**Abstract**

This article aims to initiate a discussion on the demarcation of the ethics of care. This discussion is necessary because the ethics of care evolves by making use of insights from varying disciplines. As this involves the risk of contamination of the care ethical discipline, the challenge for care ethical scholars is to ensure to retain a distinct care ethical perspective. This may be supported by an open and critical debate on the criteria and boundaries of the ethics of care. As a contribution this article proposes a tentative outline of the care ethical discipline. What is characteristic of this outline is the emphasis on relational programming, situation-specific and context-bound judgments, a political-ethical perspective, and empirical groundedness. It is argued that the ethics of care is best developed further by means of an intradisciplinary approach. Two intradisciplinary examples show how within the frame of one discipline other disciplines are absorbed, both with their body of knowledge and their research methodology.

3

# DEMARCATION OF THE ETHICS OF CARE AS A DISCIPLINE

Discussion article

## Introduction

With a history of just a few decades the ethics of care is a fairly young, emerging discipline within philosophical and theological ethics.[1] It is rooted and further developed in feminist ethics, moral theory, theology and philosophy.[2,3] The ethics of care is a steadily evolving discipline that has moved far beyond its original formulations. Whereas the starting point of the ethics of care was the private realm of life, such as family and maternity, it has expended gradually to fields of law[4], political life[5], international relations[6,7], nursing and medicine[8,9], and organization of society.[10] The ethics of care evolves by adapting itself to those new fields coming in contact with other disciplines. This involves the risk of messing things up and becoming contaminated as a discipline. Therefore the challenge for researchers in the ethics of care is to expand as a strong discipline with a clear identity.

The inspiration for this article springs from our discovery of shared feelings of tension in using several disciplines while working in the ethics of care, without being trained as an ethicist, and to find a disciplinary niche. As we each study a topic that appeared to be important from a care ethical perspective but that is not yet fully developed by it, we take advantage of knowledge from other disciplines. However, these disciplines all have their own traditions, natures of existence of what is under study, and epistemological and methodological frameworks. Therefore, the challenge we face is to understand and, at least partially, integrate and mix the other frameworks with our own.[11] Subsequently, since lending from and mixing varying disciplines and backgrounds carries the risk of losing the heart of the matter, we need to ensure to retain a distinct care ethical discipline.

In this discussion article we elaborate on this tension. We first consider the question of disciplinarity in general. Second, we show how the ethics of care has been developed and continues to develop as a means of illustrating the problems and possibilities of multi-, inter-, trans-, and intradisciplinarity. In order to contribute to the further development of the ethics of care, we thirdly give a first attempt to demarcate the boundaries of an ethics of care. This is done

by presenting four essential criteria that should sharpen our focus in developing an ethics of care as a discipline. Finally, we present two intradisciplinary attempts that keep the care ethical identity upright.

**Academic disciplines are quasi stable**

What is a discipline? The *Oxford Dictionary* defines a discipline as an area of knowledge; a subject that people study or are taught, especially in a university. Krishnan[11] lists six characteristics of an academic discipline. Not all disciplines have all six characteristics; it depends on their stage of development. A full-grown discipline has 1) a particular object of research, 2) a body of accumulated specialist knowledge which refers to their object of research and is specific for their discipline and not shared generally with other disciplines, 3) theories and concepts that can organize the accumulated knowledge effectively, 4) specific terminologies or language adjusted to their research object, 5) developed specific research methods according to their research requirements, and 6) some institutional manifestation in the form of subjects taught at universities or academic departments.

Shneider[12] believes that each scientific discipline evolves sequentially through four stages. Stage one introduces a new language to adequately describe the matter. At stage two, scientists develop a toolbox of methods and techniques for each discipline. Most of the specific knowledge is generated at the third stage, at which the highest number of original research publications is generated. The purpose of the fourth stage is to maintain and pass on scientific knowledge generated during the first three stages.

This analysis of the development of disciplines tells us scholars that we need to know our position in the landscape of disciplines. In order to be able to appropriate and promote the methodologies, behaviors and ways of thinking of our discipline, our work should be accompanied by mapping out the boundaries with other disciplines. However, this is not an easy task as disciplines in general are quasi stable. They are continually subject to the opening of new or revised ways of framing problems, theorizing, and investigating. Because most disciplines have core and peripheral elements as well as highly specialized sub-fields, they are only partially integrated.[13]

## The emergence of a care ethical discipline

The young discipline of the ethics of care was with Gilligan's[14] methodological and epistemological critique on Kohlberg's model on moral development multidisciplinary from the start. As the ethics of care is emerging to a full grown discipline, our concern is that this process will not become polluted. When looking at the development stages of Shneider[12], we believe that the ethics of care is now slowly moving from the second into the third stage. A language to describe new objects and phenomena was created in the past decades, and during the last years most of the major methods and techniques were developed. This process is still ongoing, but in some places the time has also come that researchers with their brand new toolbox enter the field to further study specific matters.

It is in several ways that the ethics of care encounter other disciplines during this evolutionary process. As we have seen, the multidisciplinary beginning was characterized by scholars from different disciplines who worked on various parts of a common problem. A multidisciplinary approach draws on knowledge from different disciplines but stays within the boundaries of those fields.[15] Researchers representing different fields contribute methods and ideas from their respective disciplines toward the analysis of a particular research question.[16] The idea is that a research problem is cut in pieces and each piece will be addressed by the expert of one of the disciplines. One potential difficulty is the question whether or not problems can be cut in small pieces and be addressed in separated parts. The lack of shared vocabulary between the participants remains a challenge in such collaboration. In this kind of work there is no integration of concepts, epistemology, or methodologies.[17] The disciplinary perspectives are not changed, only contrasted.[15]

However, with the realization that multiple people were working on the same issues, and with the rise of a dialogue between them, the care ethical approach has taken on a more interdisciplinary structure nowadays. Interdisciplinary research also refers to the cooperation of multiple disciplines to solve a question, but it is different from a multidisciplinary approach in that the collaboration leads to new knowledge extensions that exist between or beyond the boundaries of the original disciplines. The interaction can vary between explicitly exchanging and integrating the concepts, methodologies and epistemologies, resulting in a mutual enrichment.[17,11]

At the same time, we can also recognize forms of transdisciplinarity in the ethics of care. This means that at several places, scientists from different disciplines collaborate with non-scientists leading to an integration of needs, experiential knowing ("know how") and scientific knowledge. The call for transdisciplinarity is also political in nature as it is about the

democratization of science, the enhancement of its social embedding and legitimacy and the revaluation of what counts as knowing or knowledge.[17]

We believe and encourage that the ethics of care is slowly moving towards intradisciplinarity, as all relevant knowledge sources and methods are combined in a coherent discipline. One scientific discipline may borrow methods and knowledge developed by another discipline for their own use.[13] In an attempt to explain the differences between the varying forms of integration, Nissani[18] offered the illustrative metaphor of mixing fruits. Fruit (apple, mango, orange, etc.) may be served alone (disciplinary), in a fruit salad (multidisciplinary), or blended as a smoothie (interdisciplinary). Extending this metaphor to intradisciplinarity, one might imagine using the smoothie as the basis for a new dessert. See Figure 1 for an illustration of the four forms of disciplinarity.

The development toward intradisciplinarity is more than an epistemological issue. It is also a practice of cooperation, and thus of deliberation: doing research together. In that sense the discipline formation can hardly be seen as an idea-designed project. It is a practice, and we are, with other scholars, doing it. This also means that there is no authority above the parties that can decide what should be in or out of the discipline. Nevertheless, one can see that in the stages of discipline formation knots are being cut.

Above all, in order to be able to cross a boundary there need to be boundaries in the first place and one needs to know where these boundaries are. This is also illustrated by the fact that hard sciences with well-defined boundaries would find it much easier to cooperate with other disciplines than the soft sciences, as the latter have far less defined boundaries and are therefore more penetrable and open to criticism.[11] The lack of an open and critical debate about the delineation of the ethics of care invites us to work out four criteria, or rather fundamental ideas, that we believe must be recognizable in care ethical works. This tentative demarcation of an ethics of care may serve as an opening for further discussion on the care ethical discipline.

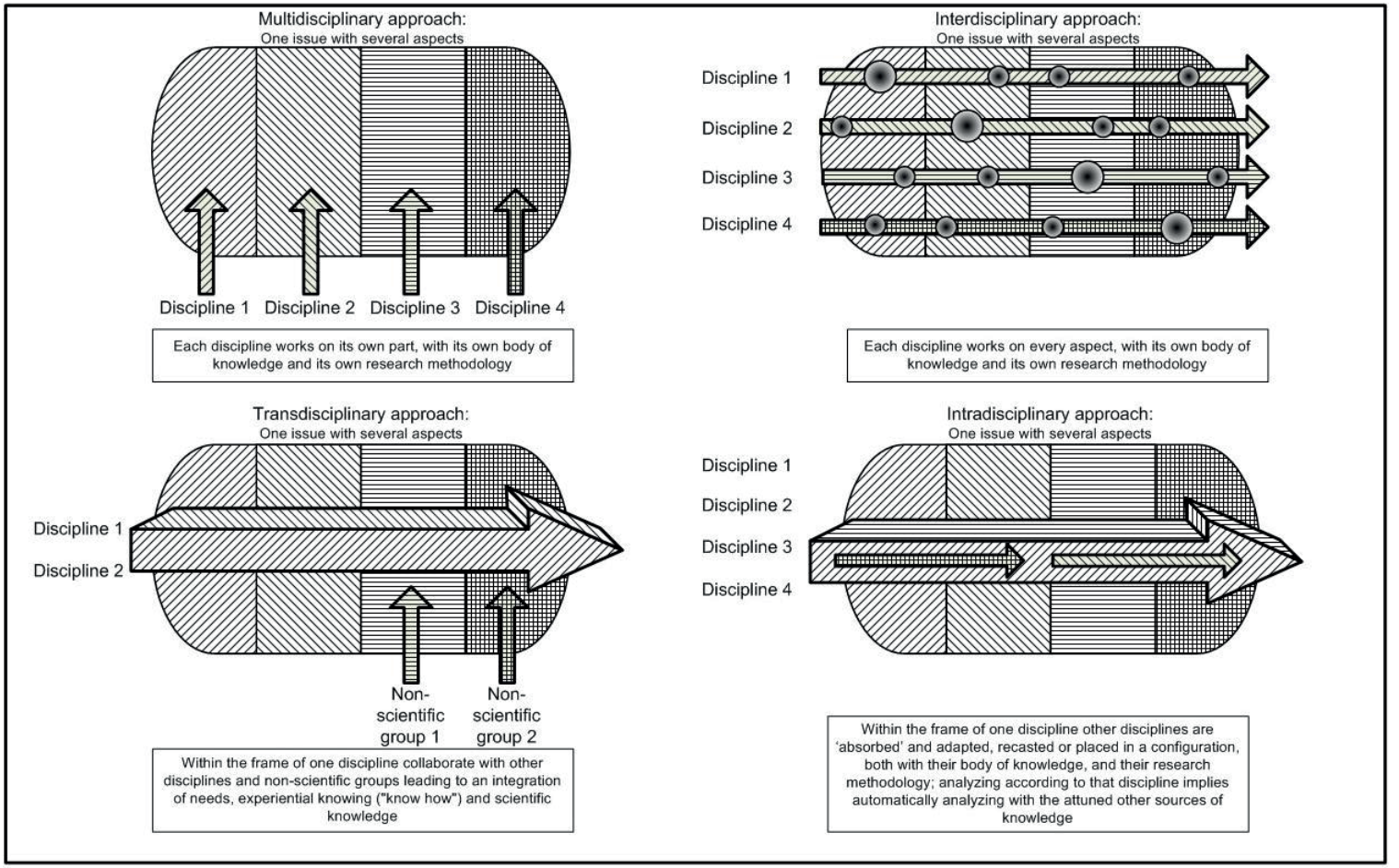



**Figure 1.** Four disciplinary approaches

**Criteria for the further development of an ethics of care**

In our opinion, the following four features are necessary to speak of an ethics of care: a) relationship based programming, b) recognition of situatedness and contextuality and therefore judgments are not generalizable (particularity), c) care ethics is a political ethical discipline, and d) the theory is empirically grounded or at least informed. The first three criteria are in agreement with the international development trends of the ethics of care. We present our specific interpretation of these widely taken over assumptions. In the context of this discussion article, we have furthermore added the fourth criterion of groundedness. However, it is possible that other care ethicists might argue for other directives. Carefully inventing the criteria of the ethics of care is work in progress that we think should be more transparent. The criteria will now be further explored.

(a) As was carefully thought out by Gilligan[14] and Noddings[19] and later widely adopted, the ethics of care focuses first and foremost on an ethical emphasis on relationships. Persons, communities and organizations are conceptualized as relational and interdependent.[20,21] Care is fundamentally relational and by using the term relationship based programming[22,23], we conceive this relational aspect quite radically, assuming that relationships have five major functions in care. First, the relationship is a source of knowing: it tells us what is needed.[24,25] Second, the relationship functions as the restraining framework for the tuning of care: it tells us how much to give, when to stop, etc.[26] Third, the relationship is the place where one receives recognition and care.[27] Fourth, the relationship acts as the source of legitimation.[28,29] Fifth, the relationship can be a stage on which the other can appear in a broad sense instead of through the lens of diagnosis or preset categories.[30,31,32]

(b) Secondly, the ethics of care is context-bound and situation-specific.[33] One can discern three forms of context: the physical context such as the place where you live, the social context that assumes that everyone is in a relational network, and the historical context that takes into account someone's biography. The more details one abstracts, the more one goes away from the situation. Ethical thinking should therefore be as specific (non-abstract) as possible. As a result, arguing in the ethics of care is not based on principles, but rather on basic insights or understandings. Generalizability of judgments is not a substantial criterion in the ethics of care. Moral judgement can be found in the decisions in specific situations. This is again a radical aspect, as it means that care needs local validation of meanings. Local validation means that the outcome of care can only be known through the receiver's experience, which itself is embedded in and dependent on relationships (criterion 1).

(c) Thirdly, the ethics of care is a political ethics. It reconceptualises traditional notions about the public and the private.[20] The scopus is broader than personal relationships; it also turns to institutional and systemic realities. As such it is a critical and in its essence a political-ethical approach.[27,36] As a political ethics, the ethics of care examines questions of just institutions in a decent society, including the distribution of social benefits and burdens, legislation, governance, and claims of entitlement. Professional care is considered to be a formalized activity which is always embedded in larger social practices and relational networks. These latter networks provide the particular context in which the moral good can emerge.[37] Thus the ethics of care places individual actions of human beings in a broader framework of attentiveness, responsibility, competence and responsiveness.[33]

(d) Fourthly, and this characteristic is derived from the previous ones, the empirical and ethical knowing are specifically related to each other. As ideas exist in a particular context and unfold their meaning there, the ethics of care should emphasize the empirical, detailed study of practices. The good is emergent and shows itself in practices: good is what turns out to be good.[37] This implies a revaluation of the epistemological process. It is not just about rational approaches and decontextualized abstract knowledge; rather emotions and tacit knowing are also valued as important epistemological sources, which therefore have to be critically cultivated.[20,21,37] In care ethical literature, care is most often defined as a value, disposition, or virtue, and is frequently portrayed as an overlapping set of concepts.[20] We associate ourselves with one of the most popular definitions of care, offered by Tronto, which construes care as "a species of activity that includes everything we do to maintain, contain, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment".[33] This definition posits care fundamentally as a practice. Understanding care as a practice rather than a virtue or motive, resists the tendency to romanticize care as a sentiment or dispositional trait, and reveals the breadth of caring activities as globally intertwined with virtually all aspects of life. The term "practice" brings in the elements that will continue to be important when it comes to the understanding of care, such as criteria (what is good care?), virtues (excellent properties or characteristics of caregivers), responsibilities (who does what?), and values (what is care actually about?).[34] This should encourage care ethicists to undertake research in practices with professionals, patients, and their fellows. To strengthen ethical normativity, we believe ethics of care should be as much empirically grounded as possible. For methodological issues this would

mean a reciprocating movement between critical conceptual, hermeneutic, phenomenological and qualitative[9] empirical research.

It is not easy to provide guidelines for what is (part of) the ethics of care and what is not. There are many publications that are grouped under the ethics of care, but most authors are not explicitly concerned with the question why and how their work stands in the care ethical tradition. Therefore, an interesting question would be whether it is possible to tentatively say something about the landscape of the care ethical discipline by using these initial criteria for some care ethical publications. One would probably find that some of these publications lay at the heart of the discipline and others on the boundaries, which makes it all the more striking that the authors barely reflect on the care ethical nature of their work. However, to make such a comparative attempt is beyond the scope of this article.

As a further contribution to the debate on the criteria and boundaries of an ethics of care, our own studies will be presented in the following section. We propose that we have found two intradisciplinary paths that meet the care ethical criteria.

**First path: recasting**

As we have seen, intradisciplinarity means that within the frame of one discipline other disciplines are absorbed, both with their body of knowledge and their research methodology. Analyzing according to that discipline automatically implies analyzing with the attuned other sources of knowing. In the study of one of the authors of this article (Klaver), *attentiveness* is the core concept of the research project. We will show how insights on attention coming from varying disciplines are *recasted* and as such integrated in a care ethical study of attentiveness.

Tronto[33] has shown that the process of care starts with the recognition of a need and the first moral aspect of caring is therefore considered as attentiveness. Furthermore, from research into the experiences of care receivers we know that good care is about recognition: it comes to the experience of being seen.[27,28,36] This means that attentiveness and care are internally connected: without attentiveness good care cannot exist.[7,33,38]

Despite the importance of attentiveness, it is, as an ethically relevant concept, hitherto poorly defined and little studied.[39] Therefore, an empirical study is undertaken to describe how attentiveness appears in care practices. On the basis of experiences of patients and caregivers in a hospital, Klaver tries to describe the nature, elements, and determinants of attentiveness, thereby

[9] The choice for research methodology depends on the research question. Quantitative methodologies may also be helpful to explore what is going on in ethically sensitive care practices, but qualitative research lends itself better for reconstructions of the meaning of lived experiences.[35]

having an eye for political aspects such as power relations or how oppressive systems work. The study does not aim to provide general statements about attentiveness, it rather describes how it comes to the fore in different situations. The practical purpose of this undertaking is to provide more grip on the difficult concept of attentiveness, in order to be able to understand and analyze care situations under this perspective.

As a background for this study, a theoretical framework is developed providing the sensitizing concepts necessary to study attentiveness empirically. As attentiveness is studied by many different disciplines, this framework is fed by insights from psychology, philosophy and phenomenology, theology, spirituality, and literature and art theories.[39,40] However, the researcher has a *care ethical* interest in attention. This means that the ethics of care, with the criteria described in this article, serves as a selective mechanism and synthesizing power: it helps to determine what insights on attentiveness or attention are and are not relevant - and why it is so. Insights from other disciplines are rewritten to fit in this care ethical framework. We call this type of integration *recasting*, a word often used for an object of metal that is given a different form by melting it down and reshaping it.

In the psychological literature, attention or attentiveness is understood as the cognitive process of selectively concentrating on one aspect of the environment while ignoring other things. In philosophy and phenomenology attention is closely related to consciousness and perception. In spiritual and theological literature, attentiveness is understood as a necessary way of doing or being if we are to know other people or things. In this way a notion of attentiveness seeks to unite contemplation and action. Attentiveness is sometimes even regarded as a 'lifestyle'. It is an important concept in, for instance, mindfulness, which is a Buddhist concept that is now broadly conceptualized as a kind of nonelaborative, nonjudgmental, present-centered awareness in which each thought, feeling or sensation that arises in the attentional field is acknowledged and accepted as it is. The importance of notions from literature and art theories lies especially in the aspect of openly observing. It is what happens when people break through established patterns of observing, naming, thinking and handling.[39]

Because the literature on attention is very diverse and the consulted authors do not refer to each other, the *recasting* is accompanied by comprehensive reflection on the research problem and perspective. Through the juxtaposition of all angles one obtains a multitude of ways to think about attention, but no single perspective that is useful for the study of attentiveness in professional care practices. The absence of such a common tradition in the perspectives discussed constitutes a difficulty on the one hand, and it is an advantage on the other hand. The difficulty is that the researcher should act as mediator between the different perspectives and

should make up for the dialogue that does not exist. The advantage is that the points of agreement and disagreement can be selected in accordance with what can help the researcher to understand the findings from her care ethical type of interest for attentiveness.

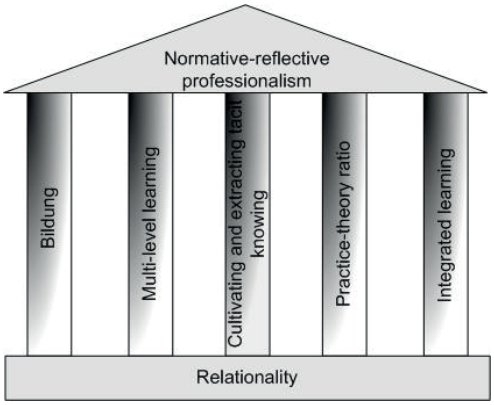
One example is the idea coming from psychology that the caregiver can focus his attention on a patient. This idea of focusing is integrated in the framework, but only after the realization that something can only be attention if the patient experiences it like that. In other words, in psychology attention is defined by the person who is attentive, but in a care ethical framework that focuses on relationships, attention is understood as something that exists *between* people. It needs both a giver and a receiver. Yet, the psychological idea of focused (and distracted) attention has been retained.

**Second path: reconfiguration**

The second author (Van Elst) takes another route to integration of the bodies of knowledge of different disciplines into the ethics of care. This route is what we call *reconfiguration*. The focus of the study is the transition of care practices in a general hospital to practices of Professional Loving Care (PLC). Professional Loving Care is a care ethical view on professionalism and can be defined as 'a practice of care in which competent and compassionate professionals interact with people in their care; to them tuning in with the needs of each individual patient is a leading principle and if necessary they modify the procedures and protocols of the institution; the main purpose of this type of caring is not repair of the patients' body or mind, but the care-receivers' experience of being supported and not left on their own; important, too, is that all people concerned in healthcare (professionals, care-receivers and their relatives) are able to feel that they matter as unique and precious individuals'.[21] Little is known about the way existing practices of care can be changed in order to provide good care in line with the ethics of care. In this project Communities of Practice (CoPs)[41,42] are used to induce bottom-up changes in the hospital. CoPs can be defined as 'groups of People who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis'.[41] Special attention is paid to the orientation of the CoPs to develop normative, reflective professional practice.

An initial *Care Ethical Learning Model* is developed by the researchers[43,44] based on earlier experiences with transitions in care[45] and on an extensive literature study. The model uses knowledge from the ethics of care but also concepts of social learning theory and change management theory.

The route of *reconfiguration* relates the different concepts in our model in a new constellation to each other so that it becomes a care ethical model. Each separate concept is not specifically a care ethical concept; reconfigurated it is a care ethical concept. The *Care Ethical Learning Model* is a reconfiguration of eight concepts. Those eight concepts are chosen in the light of the four mentioned criteria for an ethics of care. Some of them are strongly interwoven with the ethics of care, such as *relationality, normative-reflective professionalism*, and the *ax personal – political.* A Learning model also needs a specific epistemological understanding and this understanding is explained by the concept of *cultivating and extracting tacit knowing.* The other four concepts are chosen as pillars which contribute (*integrated learning, practice-theory ratio, multi-level transformative learning)* to or offer resources (*"Bildung")* for care-ethical learning. See Figure 2 for an illustration of the *Care Ethical Learning Model.*




The direction of the learning is to develop normative-reflective professionalism. This is a kind of professionalism which specifically aims at relational programming and enables professionals to make their judgments in a specific situation with eye for the context of the situation. The concept *integrated learning* is about learning processes which take place in real and complex practices. The focus is not only on learning, but also on developing normative-reflective professionalism, professional identity, quality improvement and innovation. Those parts cannot be seen separately, but are in constant relation and interaction to each other. Furthermore the (social) learning concepts such as *multi-level learning, Bildung,* and *cultivating and extracting tacit knowing* are embedded in a relational, political framework. *Multi-level learning* is a non-hierarchical four level concept. This concept not only focuses on (1) learning competencies but also on (2) reflecting on the level of intensions and guiding principles, and (3) reflection on the paradigms of health care. The fourth level is learning how to learn and to reflect on each of the three earlier mentioned levels. *Bildung*

is a coherent set of group activities to develop individuals by offering more than only cognitive resources. Also cultural (plays), narrative (books) and emotional registers are nurtured. *Bildung* within this learning model focuses on developing critical thinking and the ability for care professionals to morally judge. This contextualization follows the care ethical criteria. Learning can initiate profound personal and institutional changes. The revaluation of tacit knowing and emotions can also be seen as political: it is about tampering with existing hierarchic epistemological structures. Within the complex *Care Ethical Learning Model* emergent properties can only be understood by looking at the relations between the concepts. The non-linear mutual influential relationships between the concepts make it specifically care ethical.

## Conclusion

How care ethicists can be open and critical about the care ethical nature of their work is a challenge for care ethicists today. By describing disciplinary development in general, positioning the ethics of care, presenting different forms of disciplinary integrations, and the proposing of a tentative demarcation of an ethics of care, an attempt has been made to offer a way to deal with this challenge. The tentative outline of the care ethical discipline could be used as a viewpoint from which to reflect on this difficult question. What is characteristic of this outline is the emphasis on relational programming, situation-specific and context-bound judgments, the political-ethical perspective, and empirical groundedness. As a further contribution, our own two studies were presented, which are two intradisciplinary approaches that keep the care ethical identity upright. We believe that scholars should continue on this path when it comes to developing the ethics of care. There could be other ways to deal with the problem though, which reaffirms the need for further discussion on this topic.

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Background story 1:

# A WORKING DAY OF AN ONCOLOGIST

**Start: 7.55 a.m. in his own office**

The oncologist changes clothes in his own work room. The pager goes off and he answers by phone. This is about a patient he needs to check on later. Then he gets a cup of coffee and walks into the college hall.

**Radiology and morning meeting, 8.00 a.m.**

Every morning, all residents and staff gather for a meeting to discuss the patients, the difficulties at the wards, and daily practicalities such as the availability of beds for emergencies, or the distribution of tasks, especially if one of the physicians is absent. Last night, two patients were admitted to the ward. Their situations will be evaluated this morning.

**Outpatient department: 8.30 a.m.**

10 patients have an appointment scheduled this morning. First, the oncologist takes a coffee. Then he takes a short look at the files taken care of by the assistant, and invites the first patient into the consulting room. Since there are no new patients scheduled this morning, he is familiar with each one he will see. He starts most conversations with a short outline of previous problems, asking the patient how they are doing now. He tries to find out more about specific somatic problems and about medication. Sometimes, they have a brief chat about a specific hobby or other personal things. He has no trouble talking to the patient and making notes in the digital file at the same time. He discusses the results of the tests most patients have had a few days before (blood, scans, etc.), and relates these results to the issues at hand. Some of the patients need an examination, which takes place at the other side of the room on a bench behind a curtain. The oncologist washes his hands afterwards. He then explains to the patient whether they need to continue the treatment or to change certain elements in medication, and he discusses when to meet again. For most patients, he fills out forms for ordering tests that should be done before their next appointment. He shakes hands with the patient before they leave his room. In the same corridor, a specialised nurse receives patients as well. She steps into his office

twice this morning to ask for his advice. He also gets a few phone calls about patients on his ward and three visits from colleagues dropping by.

**Lunch and e-mail, in his own room: 12.30 a.m.**

He buys sandwiches at the restaurant and eats them in his own room. In the meantime, he calls a few people to talk about patients and trials, and he checks his e-mail.

**Pathology lab meeting: 1.00 p.m.**

The pathology meeting is in the laboratory. In this room, the display cases along the walls are filled with old medical books and historical equipment and tools. There is a large screen on which a lady is projecting cells, using a microscope and several slides which show an augmented version of blood or human tissue. In the front of the room, closest to the screen, are the specialists. Behind them, to the side of the room, are the residents. At the back, the interns and some people from the lab. Many attendees use this meeting to have lunch; sandwiches and salads are unwrapped and consumed. Everyone listens enthralled to the presentation of the laboratory lady. She talks passionately about what can be seen on the screen and what the image indicates in terms of pathology. In her story, the little cells actually look like people who have their own subgroups, and show all sorts of behaviour. I ask the resident doctor next to me what the images tell him, which is not much. He recognizes some things but it is an art in itself to make sense of those cells, he adds. Sometimes, someone asks question. This is a tricky affair: this is a time and place to show how smart you are. Smart comments are being complimented and stupid comments are being punished. One of the residents asks the lady to tell a bit more about the veins. What follows is laughter, snorting and muttering. "What?", everyone laughs at her, "*all* about it?". Apparently, hers was a stupid or irrelevant question.

**Visit to secretaries, 2.00 p.m.**

In the secretariat, there is a series of letters and some forms that are ready to be checked and signed. The oncologist sits down and has a chat with the secretaries.

**Wards: 2.20 p.m.**

The oncologist enters the doctors' room near the ward. He sits down at the intern's computer (who is away at the moment) and makes a comment about him not having logged out. "That is so annoying! Nobody ever logs out. It irritates me to death, I'm always logging out people before I can log in myself.' The doctors cautiously laugh. 'It is quite crowded here', the oncologist

continues, and he looks around the room. There are two residents, two interns, one nurse, and me. 'This is a researcher', one of the interns says, and the oncologist looks at me. 'You are a researcher? And what do you study?' I do not answer, only look at him. He definitely knows who I am. Then he says 'ooohhh yes', and changes subject.

It appears that one patient's condition has actually even been made worse by the administered medication and it has been found that treatment wouldn't have been necessary. She can now go home, and fortunately nothing went wrong. 'So, we have only made the patient sicker', the oncologist observes. 'Yes, actually', the resident answers, and then he wants to move on to the next patient. 'Yes, but that's very serious', the oncologist continues, and he elaborates. 'There has recently been an investigation on complications of medication which shows that patients are often actually made sicker in the hospital. That appears to happen quite often. For example, you visit a doctor because you feel a pain in your chest. At that time, no cause can be found, but they send go home with beta-blockers, aspirin and what not. Those patients usually keep taking those medications for over a year before they are allowed to stop. Health insurers are quite happy about this...'. His pager buzzes several times. He takes the resident's phone to make a call, and meanwhile keeps the intern's computer occupied. The intern and the resident can do nothing until the oncologist has completed his call and continues the discussion.

**Back to OPD: 4.45 p.m.**

The oncologist is returning to the outpatient department again. He has to make some phone calls.

**One more patient: 5.45 p.m. at the ward**

There is one more family meeting at the ward. Yesterday, a patient heard that she has cancer. She and her relatives were quite upset, and they seemed unable to absorb more information. Therefore, the oncologist sent them home and asked if they could come back today to have an extensive conversation with him and the resident about the options for treatment. After this meeting, the oncologist makes a stop at the desk of the nurses. 'Everything OK here?' He wants to prevent them from calling him when he has just left the hospital. He sees a trampled biscuit on the ground. 'Oh yuck guys, nasty!', he hurriedly picks it up and washes his hands.

**Going home, 7.00 p.m.**

The oncologist changes clothes in his own room and leaves his white coat there.

# 4

# ATTENTIVE CARE IN A HOSPITAL

## Towards an empirical ethics of care

Klaver, K. & Baart, A. 2011 *Medical Anthropology: A journal about health and culture* 23(2): 309-324

**Abstract**

This article is an introduction to our research on attentiveness in hospital care. It presents the theoretical framework in which we carried out our qualitative empirical research, thereby providing an insight into the combination of the ethical and the empirical perspectives. This is done (1) by exploring the different definitions of attentiveness and thereby developing our own definition, and (2) by explaining our empirical approach to attentiveness. Habitus comes to the fore as a fruitful research instrument, and attention is shown to be part of the core business of medicine. However, attention has many facets, and not all of these are equally present in hospital care. It becomes clear that attentiveness can only have its good meaning and effect if it is the right kind given at the right time. Caregivers frequently succeed in showing the proper attention, yet this is often done tacitly: attention is not an easily accessible subject matter, and caregivers do not always use the term "attention." Several fieldwork cases are presented through which the complexity of attention becomes evident.

# 4

# ATTENTIVE CARE IN A HOSPITAL

## Towards an empirical ethics of care

### Introduction

The painting *The Attentive Nurse* of the 18th-century French painter Jean-Baptiste-Siméon Chardin invites us to think about the nature of attentiveness. It shows a woman wearing light-coloured clothes and an apron, with white sheets hanging over her arm and an egg in her hand. Next to her are some pans, a table with a jug of water, bread, and a plate. The nurse's face is perhaps the painting's most important element: it is tender, patient, and soft, but also resolute and strong, and extremely concentrated. Imagining being this nurse's patient, who is not depicted in the painting, makes us feel confident, trustful of this woman preparing a meal with such great devotion.

Attentive care speaks to one's imagination. This is illustrated by the many care institutions advertising that they provide "attentive care". Attentiveness appeals to people who require caregiving for themselves or a family member. Research shows that, according to patients, attentiveness is a crucial component of good care (Johansson et al 2002; Radwin 2000; McWilliam et al 2000). At the same time, however, attentiveness is being put under more and more pressure in contemporary health care. Attention is a hot topic in care, which is also shown by the rise of concepts like 'attention minutes' (*aandachtsminuten*) and 'attention officers' (*aandachtsfunctionarissen*). The importance of attentiveness in the context of care might seem obvious; however, there is no unambiguous definition of the concept, which is used in various ways. It is not clear how attentiveness should be characterized, what it consists of, and what is needed for attentive care. Our qualitative empirical study attempts to investigate and analyze the specific forms and aspects and appearances of attentiveness found in a hospital in the Netherlands. Such a configuration comprehensive analysis of attentiveness contributes to the understanding of the caring side of health provision, a side that is often neglected in the usual deliberations about quality of care but that seems to be highly relevant from the patients' perspective. Attention to attention is what we need; and an insight into its specific characteristics may be the first step towards more room for attentiveness in health care.

This article discusses the existing multi-disciplinary literature on attention, from which we extract our own working definition of attentiveness. Then we present and explain the research question behind our empirical study: where(in) does attentiveness exist in the work of care professionals and in the experiences of patients? It shows how the concept of *habitus* may contribute to a proper understanding. How does attentiveness relate to *habitus*? Is attentiveness embedded in the *habitus* of doctors and nurses? If so, how? And if not, why not? Trying to answer these questions may provide a deep insight into the chances and obstacles of attentiveness in hospital care.

**Attentiveness**

This section discusses the existing multi-disciplinary literature on attentiveness, thereby exploring the different uses of the concept. This conceptualization, or theoretical framework, provides the researcher with the sensitizing concepts necessary for understanding the broad and complex phenomenon of attentiveness. Empirical qualitative research is needed to understand attentive care in hospital practice.

Both attention and attentiveness are studied in various ways in the different disciplines. In the psychological literature, attention is understood to be the cognitive process of selectively concentrating on one aspect of the environment while ignoring other aspects. Focalization and concentration of consciousness are of its essence. Examples include listening carefully to what someone is saying while ignoring surrounding conversations and listening to a cell phone conversation while driving a car (James 1890; Deutsch & Deutsch 1963; Zomeren & Eling 1997). What we learn from the psychological literature is that attention is involved in the selective directedness of our mental lives. The nature of this selectivity is one of the principal points of disagreement between the extant theories of attention. The instances of attention differ in several dimensions: in some cases attention is a perceptual phenomenon; in others it is a phenomenon related to action. In some instances the selectivity of attention is voluntary; in others it is driven, quite independently of the subject's volition (Stanford Encyclopaedia of Philosophy). Attention is of philosophical interest because of its apparent relationship to a number of other philosophically puzzling phenomena. There are views suggesting that attention is closely related to consciousness. It is controversial, however, whether the relationship of consciousness to attention is one of necessity or sufficiency (or both or neither). There are also perspectives linking attention to demonstrative reference, to the development of an understanding of other minds, and to the exercise of the will (Waldenfels 2004; Arvidson 2006; Steinbock 2004).

Beside this neuro-psychological and philosophical literature on the phenomenon of attention, there is an extensive amount of philosophical and spiritual work that focuses on the moral value of attention. In this literature, attention or attentiveness is understood as a necessary way of acting or being in order to know (or to help) other people (or things). On this view, attentiveness can be good in itself. According to Murdoch (1970) attention is "an imaginative and normative use of moral vision that burns away the selfishness of natural human desire, leaving behind the purified desire of just and compassionate love". Weil (1951) writes that attention is crucial for every human interaction. Attention is focused on the other and asks for the suspension of one's own thoughts and opinions. It is waiting, open, and willing to receive the other. It entails a certain passivity, a lack of will, at least initially. Verhoeven (1972) treats the concept of attentiveness when he writes about wondering, which he describes as a way to go beyond the obvious understanding. When people wonder, they break through established patterns of observing, naming, thinking and handling. In other words: it is not about categorising someone, but about aiming to learn to know slowly and openly. These works make it clear that attentiveness has to do with recognition: it is all about *seeing* the other. Furthermore, attentiveness is an important concept in mindfulness, a Buddhist concept that is now broadly conceptualized as a kind of non-elaborative, nonjudgmental, present-centred awareness in which each thought, feeling or sensation that arises in the attentional field is acknowledged and accepted as it is. Benedictine spirituality also gives attentiveness an important role, with its maxim: whatever you do, do it with attention (Casey 2005).

As has become is clear, attentiveness is an interdisciplinary concept. In the ethics of care tradition, attentiveness is described by Tronto in her book *Moral Boundaries* (1993). Tronto analyses care and describes four[10] phases, which, although conceptually separated, are interconnected when put into practice. She first mentions *caring about*, which involves the recognition that care is called for. It means perceiving the existence of a need and assessing that this need must be met. Often it will involve assuming the position of another person or group to recognize the need. The next phase in the caring process is *taking care of*, which means assuming some responsibility for the identified need and determining how to respond to it. It also means involvement in organisational activities. Third, Tronto describes *caregiving* as the direct meeting of needs. This involves physical work, and almost always requires that caregivers come in contact with those in need of care. The fourth phase is *care-receiving*: this final phase recognizes that the person in need of care will respond to the care received; the patient feels better. What was meant

[10] In 2013, Tronto added a fifth phase (Tronto J. *Caring Democracy. Markets, equality, and justice.* New York: University Press, 2013).

to be good care should be experienced as such. Tronto includes this phase as it provides the only way to determine whether the care needs have actually been met: sometimes it is hard to identify the need, and in this phase one can check whether it has been done adequately. And even when the perception of the need is correct, the issue of how to meet the need can cause new problems. Tronto couples these four elements with four ethical elements of care, namely, attentiveness, responsibility, competence, and responsiveness. She describes attentiveness as the quality to open oneself to the needs of others.

Baart (2004) defines attentiveness as a socially inclusive act in his theory of presence (2001). He states that what can be good for a care receiver is not always clear from the beginning but is shown in the interaction between caregiver and care receiver. Attention lies at the heart of his work as he begins his description of presence as "a practice in which the caregiver attentively concerns himself with the other, thereby learns to see what is at stake for the other, from desires to fear, and in relation to that tries to understand what can be done in a particular situation, and who he could be to the other" (2004: 40-41 [our translation]). Baart elaborates on the socially inclusive act of attention and shows that it has a double character. He theoretically distinguishes instrumental attention (i.e. to come to a good diagnosis) from beneficent attention (attention for the sake of attention). He emphasizes that attention understood in this latter way is a tricky phenomenon, since it can have a violent character as well as a beneficent one: attentiveness might be related to discipline or control (e.g. by governments, insurance companies).

Our study of attentiveness in caregiving is conducted from an ethics of care perspective. However, we define attentiveness in the broadest and most comprehensive sense, making use of all perspectives described above. Attention is approached as a social phenomenon, and therefore is located at the intersection of attention as a cognitive capacity and attention that expresses itself as care or love. We focus on the beneficent meaning of attentiveness, but its violent meaning will not be forgotten. Beneficent attentiveness is understood as a practice that can, from two sides, create a space in which a relationship may arise. It is the difference between a care connection simply for instrumental reasons and a relationship between a caregiver and a patient in which *good* care can be delivered, that is, care that is received as care, care that makes people feel better. When attentiveness is understood as creating such an intersubjective space, the focus is on neither the caregiver nor the patient, instead the emphasis is on the relation. Indeed, in claiming the importance of attentiveness in care, we are opposing the dominant contemporary view in which care is no more than providing service in a market-oriented, commercial and effective way. With Van Heijst (2005) and others in the ethics of care tradition, we argue for a different discourse when thinking about care, in which care is anticipating someone's neediness or

dependence. Competent, technical, medical care is extremely important, but only on the understanding that caregivers realise that reparation of problems, relief of pain, or curing diseases is never a goal in itself. The overall goal of every form of caregiving is to stand by someone who is in pain or misery (ibid.).

**An empirical study from an ethics-of-care perspective**

Having developed a broad definition of attentiveness through engaging the existing literature, we now address the research question of our study: where(in) does attentiveness exist in the work of care professionals and in the experiences of patients? To find an answer to this question, we conducted an empirical interpretative qualitative study in a general hospital in the Netherlands. We used ethnographic research methods, such as participant observation and interviews, and we tried to shed light on the perspectives of both caregivers and care receivers.

As noted, this study is undertaken from an ethics-of-care perspective. This seems to be at odds with a qualitative-interpretative research design that aims to understand the experiences and considerations of people on their own terms and in their social and institutional context. However, it has become obvious that it is impossible to conduct a study in a value-free and theory-free way. Interpretative research takes place from a certain perspective, however explicitly that may be acknowledged and formulated. Taking a perspective implies regarding certain questions as more important than others and certain answers as more relevant. Our use of an ethics of care perspective and the theoretical conceptualization of attention interact with our interpretative qualitative research. Reflection on this perspective is the key: on the one hand, the perspective drives our questions; and on the other hand, this perspective is developed further through the input of the collected data (Gremmen 2001).

How are we to understand attentiveness in hospital care? Attention is difficult to grasp, as it cannot be directly observed. This leads to some important implications for our empirical study. As we realize that people do not always consciously reflect on their attentiveness, or their receiving of attentiveness, our study looks not only at people's *action* but also at their *behaviour*. It focuses not only on the reflective aspect of attentive caregiving but also on the pre-reflective or subconscious aspect of it. In other words: as the definition of attentiveness is unclear, we do not merely ask people what they think of this phenomenon; rather we try to gain insight into how they experience it. This means that our study takes into account the influence of contextual factors on the way in which attentiveness takes place in practice: the character of the hospital contributes significantly to the appearance of attentiveness. However, although we explicitly

mention the importance of context here, we do not see context as something outside of individuals. We seek to avoid this separation in our approach, as we argue that structural factors do not only exist in the context of the wider social field of the hospital but are also embedded in individuals.

Considering these implications for an empirical study of attentiveness, the concept of *habitus* as developed by Bourdieu (1990; 1977) proves to be a useful research instrument. The notion of *habitus* helps us overcome the division between individuals and context, as it provides a framework to understand the embodied character of structures, their generative power and their relation to the wider social field. In this way it may assist our study approach, and the ethics-of-care tradition in general, as it helps protect us from two pitfalls: the tendency to regard everything concerning attentiveness as a hyper-individual matter, and the risk of attributing all that happens to contextual, external structures.

What is *habitus*? *Habitus* is a concept developed by the sociologist Bourdieu in relation to the concept of field. The concept of field refers to social space. A field is a relatively autonomous space, built around specific positions and institutions and with an internal logic of its own. A social space can be called a field when there is something at stake and people are willing 'to play the game' (Bourdieu 1989). While the concept of field denotes the external social structure of a world, the concept of *habitus* refers to the internal model of social reality. The *habitus* develops through a process of socialization and can be defined as a system of dispositions: durable, often subconscious schemes of perception and appreciation that activate and lead the way to practice. The dispositions of the *habitus* give rise to a limited number of strategies. These strategies manifest themselves in certain visible patterns of behaviour, manners and beliefs: in practices (Bourdieu 1990). Under common conditions, a common *habitus* comes into being. A common *habitus* enables practices to be harmonized objectively, without any conscious reference to an explicit norm. The practices of the members of the same group are always better harmonized than the agents know or wish (Bourdieu 1990).

Connecting these ideas of Bourdieu to our research project, the field refers to the hospital, or a particular hospital ward, and the *habitus* is found in the people working in that field, in our study particularly doctors and nurses[11]. *Habitus* proves to be a useful research tool, as it provides a framework in which structures are seen not only in the external space but also as embedded in individuals. Bourdieu, rather than stating that the active subject confronts society as if that society were an object constituted externally, developed the concept of *habitus* to demonstrate not only the ways in which the body is in the social world but also the ways in which

[11] Patients do also have a habitus, but this is beyond the scope of this article.

the social world is in the body: "It is a socialised body. A structured body, a body which has incorporated the immanent structures of a world or of a particular sector of that world - a field - and which structures the perception of that world as well as action in that world" (Bourdieu 1977: 81). Bourdieu considers *habitus* to be potentially generative of a wide repertoire of possible actions, enabling the individual to draw simultaneously on transformative and constraining courses of action (Reay 2004). While the *habitus* allows for individual agency, it also predisposes individuals towards certain ways of behaving.

How does attentiveness relate to *habitus*? This is the question at the heart of our study: is attentiveness embedded in the *habitus* of doctors and nurses? If so, how? And if not, why not? The answers to these questions may provide deep insight into the chances of and obstacles to attentiveness in hospital care.

**Attentiveness in the hospital practice**

In this section we present some examples from the fieldwork material, which together show, on the one hand, that attentiveness is embedded in the medical *habitus* and, on the other hand, that the medical *habitus* can be a hindrance to attentiveness.

> Nurse Jane tells me she has the feeling that she is busy and running the whole day. Now, right after lunch, it is a bit quieter at the ward. "Well, since I have some time, I am going to empty the catheter bags in room 3", she tells me, "and meanwhile I can give the patients some attention". While emptying the urine bags, she has short conversations with the patients. Later that day, I return to room 3, and talk to the patients about the nurse. They tell me that this nurse has had a very busy day, and that it is friendly of her to come by for a chat when she had the time. When I ask them how they have experienced this chat, they tell me that it is nice to have some distraction, to have this kind of small talk. I nod. "Could I say that the nurse gave you attention?" I ask them straightforwardly. One of the two patients smiles slightly. The other one tells me: "No, she gave us time."

> With two young doctors I am discussing my research topic. "Attentiveness?" one of them says, "that is something that takes time. We do not always have that time. But well, ok, perhaps it doesn't always have to take much time. It isn't always about talking, you can also be attentive through bodily contact, you know." His colleague nods, and both tell me that they have bodily 'tricks' to please their patients: "A hand on a leg always works!" one

of them says. And probably reacting to the amazement on my face, he further explains that patients "in general like physical contact with doctors."

In the situations above, attentiveness seems to be consciously given by caregivers. However, it is questionable whether patients in scenarios like these actually experience this attentiveness. Our impression is that there is a gap between what patients and caregivers consider to be attention. What is given as attention is not always perceived as attention. And the reverse is also true: what is received by patients as attentiveness may not always knowingly be given by caregivers. This makes clear why the notion of *habitus* can be a useful tool in our study: it acknowledges that attentiveness may happen subconsciously or pre-reflexively. Attention may exist implicitly in the medical *habitus* and in caregivers' actions and behaviour.

Mr. Balducci is in the room's third bed. He is 55 years old and has pancreatic cancer. He was admitted to hospital because of 'total malaise', as we read in the patient file this morning. Pneumonia, his file further indicates. 'Backaches' and 'broken right arm'. Mr. Balducci is thin and pale. His dark brown eyes show tiredness; they are closed when he talks to us. Mr. Balducci has problems with standing up. His body is in pain. Nurse Sara gives him instructions on how to rise with less pain. He follows her directions, but still cries out loudly when trying to sit on the edge of his bed. I feel uncomfortable. But Sara stands quietly at this side, her hand resting on his shoulder. Together with Mike, a nurse in training, she helps Mr. Balducci into the chair next to his bed. Later on, that morning, when I come back from a meeting, Sara tells me that something bad has happened to Mr. Balducci. When Mike helped him from his bed to a wheelchair, Mr. Balducci pulled himself up and at that moment his left arm made an awful noise. It is probably broken, and his right arm already was... Mr. Balducci's wife was with him when this happened, and because she was panicking she immediately called their children. A nurse took Mr. Balducci to the X-ray centre, and now the patient and his family are back on the ward waiting on the results.

I follow Sara to Mr. Balducci's room. He has several questions, on how to move properly, what to be careful of, whether he still should go out of bed from time to time, and so on. Sara emphasizes that his accident could have happened any time; prevention is impossible, as his body is so frail. [She later tells me that there is probably another tumour in his arm...] The intern [*co-assistant*] comes in; she has seen the X-ray. The arm is broken indeed, and there must follow a consultation with the surgeon to determine the best

option for treatment. She tells us she called the surgeons' department, but they told her it is not appropriate for a student to directly call a surgeon. Consequently, we have to wait until she can talk to the doctor in charge, so that he can contact the surgeon. She starts to explain that two forms of treatment are probably being considered: either they will perform an operation on Mr. Balducci to put a pin in his arm or they will give him a sort of brace, which does not require an operation. Mr Balducci's eyes are closed. His family members tell the intern that they want Mr. Balducci to be operated on. However, the intern does not respond. She tells the family to wait for the surgeon's opinion: he has to decide, together with Mr. Balducci's oncologist. After we leave the room, I ask Sara which factors influence the choice for surgery or brace. She explains that "it is not only about the arm and the fracture; it is also about the progression of the cancer. The physician might choose for a brace if it is expected that Mr. Balducci will not have a long time left to live."

In the afternoon, a surgeon comes to the ward to talk to Mr. Balducci and his family. He hasn't spoken to the oncologist yet. Again, the surgeon explains the two options, and tells Mr. Balducci that he will probably get a brace. "Operation might not be appropriate for you", he says, "perhaps it is better to reduce the pain as much as possible." After he leaves the room to call the oncologist, the family members are crying and embracing each other. Back in the office nurse Sara tells me: "I expect they will not operate on him... his liver is so weak." She asks the surgeon about it. "His liver is not a problem for surgery," he answers, "but we have to wait for the oncologist". I realise that the decision depends on the prognosis: how long will this man live? Is it worth surgery? I get the impression that this whole process is sped up because of the broken arm: the patient and his family haven't yet been informed about the bad prognosis.

After a while the surgeon comes back into the room. He explains that Mr. Balducci will get a brace. The family members do not understand. They keep asking whether Mr. Balducci is too weak for the operation. "Possibly," the surgeon answers, "but besides, the brace is the best treatment option for now." The wife and children keep asking questions. They seem a bit pushy, but this is understandable since the surgeon is ignoring their fear and their questions. They want to know how long the brace has to stay. "For a long time..." the surgeon answers, and after a short silence, "for months." It becomes clearer and clearer to me that this family does not understand that Mr. Balducci will die soon. It feels oppressive.

Reading these observations, it is easy to say that Mr. Balducci does not experience any kind of beneficent attention here, but it is difficult to put one's finger on just what goes wrong. All of the caregivers involved in this case are in a certain way very attentive, but they all have their own area of expertise. It turns out that everyone is attentive from his or her own disciplinary perspective; however no one is really attending to Mr. Balducci's experiences. Apparently, attention is not always a choice of individuals; in this case it seems to be controlled by various structural factors. In using the concept of *habitus* as a research tool, we examine the way in which structural factors may be at work, both in the external context and as embedded in individuals. For example, we consider not only the influence of external systemic pressure (Vosman & Van Heijst 2010) in the form of protocols (i.e. who should tell a patient about what news?) but also the interpretations of such protocols by the nurse, the surgeon, or others involved. Other assumptions may play a role as well: for example, the perceptions that go with the nursing discipline. Did nurse Sara act on the basis of her (implicit) idea of the nurse's tasks? Or what (tacit) ideas of professional acting do the surgeons hold? As becomes clear from this case, in trying to understand the conditions of attentiveness, it is useful to study the *habitus* of the caregivers involved. How are they used to acting? What are the unwritten 'rules' of their getting along? And how does attentiveness relate to these? From this specific description, it seems as if there is no place for attentiveness in the behaviour of the people involved. Using the notion of *habitus* may help drive the questions in a fruitful direction when trying to discern which aspects may play a role.

> The assistant physician (AP), accompanied by an intern, makes his rounds on the ward. In room 2 he sits down next to a patient's bed. The patient is an elderly man whose wrinkled face looks worried.
> AP: "How are you?"
> The patient lifts his upper lip.
> AP: "Not too good, hm? With the diabetes and so on..?"
> Pt: "Hm… no… no… it's not the diabetes." [I realize that the doctor is confusing this patient with another, KK]
> AP: "[the diabetes, KK] as well, no?"
> Pt: "oh… it's the breathing… air… air…"
> The doctor realizes that he has mistaken this patient for another. He quickly takes a jotter out of his pocket, and reads his notes. Then he remembers. He briefly summarizes this elderly man's case (heart, pneumonia, kidneys) and mentions how difficult it is to find a way to 'swim' through all of his problems.

AP: "Pneumonia, that is quite something, that will last."

Pt: "I've had it before."

AP: "How did it pass that time?"

Pt: "It went well. But now it's a struggle."

AP: "We have to give it time. The body needs time. We can't do much more at this time."

Pt: "That's not what I'm asking, is it?" [short silence] "Have you looked at the medication?"

AP: "Yes. I can't really change anything of it..." The doctor explains that he is being careful not to give too many painkillers because of the patient's heart problems.

Pt: "Oh. Well. Hm. It's not to be sneezed at, you know. Last night… last night I was… I felt like… last night I felt like I was already dead actually."

AP: "Not a very cheering thought. Do you feel better now?"

Pt: "Yes. A little. But now I have to lie on my side, to prevent bedsores. After an hour of lying like this I'm exhausted."

The doctor closes the curtains around the bed and listens to the patient's lungs. The intern uses her stethoscope to listen as well.

Pt: "Now, who of you is the better listener?"

AP: "If it's alright, we are both good!" The doctor opens the curtains again.

Pt: "Hopefully they'll come soon, to move me a little bit."

AP: "Yeah, we have to ask them, to ask them if somebody can move you. How does it work with that button?" He presses the button for a nurse to come.

Pt: "Then another of those… those… those frolicking girls *('huppelmeiden')* will come…"

AP: "Yes. Er… er… yes…" He laughs a bit. Then, in a serious tone: "I know what you mean."

This description reveals a caregiver who is trying to be attentive and a patient who does not experience it that way. What happens in this case? In the first place, the conversation has a false start: the caregiver confuses the patient with another one. Fortunately, he is able to correct his mistake by summarizing the patient's condition, showing that he is on top of the situation. Then, the patient complains about his difficulty breathing, thereby asking for attention. The physician, however, reacts by giving attention to the symptoms of pneumonia. Perhaps he wants to allay the patient's worries by explaining that these symptoms fit the illness. Yet to 'justify' the complaints suggests that there is no need to give attention to them. It looks as if there are two different focuses here: the patient is seeking attention for his poor condition, while the doctor's attention is focused on explaining the symptoms. Further, the doctor tells the patient that there is nothing

he can do for him at the moment. The patient responds with "That's not what I'm asking, is it?" which can be seen as expressing a critique of the doctor. However, there is no time for the doctor to react, since the patient quickly shifts to the 'world' of the physician: did he take a look at the medication? After the doctor answers, the patient again starts to talk about his experiences; he tries to draw attention to his horrible night and thoughts. The doctor acknowledges the seriousness of the situation ("not a very cheering thought"), but instead of delving more deeply into the negativity of the thought, he searches for positivity ("do you feel better now?"). The patient seems to reject this positive thinking, continuing to emphasize his difficulties (bedsores, exhaustion). The doctor responds to this by listening to the patient's lungs, which shows that he continues to think in medical terms. The patient's question "who is the better listener?" can be understood quite ambiguously. On the on hand, in making a joke about both doctors listening to his lungs, the patient might be giving up his attempt to get attention. However, his joke might also be regarded as a form of critique; again attention is being given to the lungs but not to him. At the end of the conversation the patient once again expresses his displeasure by expressing his hope that someone will come to move him. Again, the doctor does not react to the tone of voice nor discern the underlying meaning. He simply reacts in a practical way: where is the button to call a nurse? The final appeal for attention lies in the patient calling the nurses 'frolicking girls', and this time the doctor does hear the tone in which it is said, and seriously reacts to it; however, the patient does not get the opportunity to explain this further, as the intern ignores the need for attention to the patient's bad experiences. He reacts again and again by explaining the symptoms. We do not think the intern does this consciously, as he takes the patient's complaints very seriously, but he seems to ask himself only what the words mean in terms of a diagnosis or treatment.

What does this case tell us about attention? It shows that attention is not simply good 'as such' but that, it must be focused on the right object if it is to have a beneficent meaning. Quite evidently, the attention should first find the right object before becoming focused. To achieve this, an understanding of the other person's perspective is needed. Perhaps one could say that in this case the assistant physician interprets too quickly, which causes his attention to focus on what from the patient's perspective is the wrong object. Here, we could refer to the ideas on 'wondering' (Verhoeven 1972), as it becomes clear that attentiveness involves a certain kind of seeking, a searching for meaning. It entails interpreting and re-interpreting signals, 'reading' the signs sent by the patient. How does this relate to the medical *habitus*? As we know from the literature (Nessa 1996; Burnum 1993), the search for signs, and the interpretation, evaluation and re-interpretation of signs, are the order of the day in the medical field. However, this refers

mostly to medical signs, or signs that indicate certain medical conditions. Medical caregivers try to understand and re-understand their patients, often against a background of establishing or excluding the existence of disease. Clearly, this differs from the background advocated by the ethics of care, namely, helping patients in need. On the one hand, this shows that there are opportunities for attentiveness - experienced as beneficent by patients - since the medical *habitus* allows for the search for and interpretation of signs. On the other hand, however, this sign-work is propelled from a certain motivation that only allows for those signs which caregivers feel they can professionally deal with. Medical caregivers appear to be very attentive to what patients show, but their attention is not completely open to the various kinds of signs. Some signs are more often seen and explored than others. This impression drives us to further investigate the hierarchy of signs related to the attention of caregivers.

The observation that the attentiveness of hospital caregivers is often medically driven does not exclude the possibility that patients experience beneficent attention. Sometimes, although their attention seems to be in a medically-driven mode, caregivers succeed in making space for patients to open up and truly show themselves. The following description is an example.

> The oncologist tells me about one of his patients, a 38 year-old woman with breast cancer. He tells me that he finds this a distressing case: the cancer was found when this patient was pregnant with her second child. She received chemotherapy during her pregnancy to make the tumour shrink in preparation for a mastectomy. After she had given birth to a healthy child she had to undergo the operation, which she suddenly refused. The oncologist and several colleagues have tried to convince her, but she sticks to her decision. Now the oncologist explains to me that he wants to keep her in treatment. "I don't understand her. I can't stand her refusing this probably live-saving operation. Her children are so young. [Short silence] Yeah, and what is it? I don't know. She says it isn't fear. You know, this woman thinks she will die of this disease. And she doesn't want to be *either* dead *or* maimed. That's what she says. And well, you've seen it yourself: she is very feminine... she has beautiful breasts... [Short silence] You know, I want to continue treating her. I want to keep her from feeling rejected. In the end, autonomy is the most important thing. I don't want to transfer her to another doctor... Hopefully, there will come a moment when we understand each other. Or when I can convince her." "This must be very difficult for you", I reply. The oncologist nods. "Do you try to convince her every time she comes to the policlinic?" I ask. "No", he answers,

"I just keep talking to her and continue to see whether she will change her mind or not."

The oncologist decides not to transfer this patient to another doctor. He wants to continue treating her so that she does not feel rejected. He states that it is her autonomy that is most important in the end, and at the same time he admits hoping to be able to convince her one day. From an ethics-of-care perspective, in which human beings are seen as being interconnected and giving meaning to each other's lives, one would also emphasize the importance of maintaining the relationship, and autonomy would get a more relational interpretation. This seems to correspond with the oncologist's remarks: he regards self-determination as important, but he is also concerned about his patient, and so using his expertise and beliefs, he hopes to convince her. Most important here from a care-ethic perspective is that the oncologist does not want his patient to feel rejected; he does not want to abandon her. This may be a crucial aspect of attentiveness: it is creating a relationship in which the patient may express her- or himself. Therefore it is essential that the oncologist admits that he does not fully understand the patient, but it is equally essential that this is not a settled position for him. Continuing to see whether she will change her mind, he keeps trying to read her signs. This involves two things: first he puts himself aside and suspends his own beliefs; and second he turns off his active way of doing and replaces it with a passive one. This 'waiting' for the good to come may be another key component of being attentive in care. The work of Weil (1951) could be important to understand this aspect of attentiveness. An attentive caregiver must not always actively search, interpret and re-interpret; sometimes he has to realize that attention is not always controllable, but that the 'good' will show itself. Attentiveness may require a certain 'un-knowing', a swaying with what happens, and a loosening of the reins in view of the good. That seems to go against the rules of medicine, in which everything should be mastered, controlled, and preferably evidence-based. Nevertheless, it happens in the hospital. Attentiveness requires a certain flexibility that is not always oriented towards results or targets.

These explorations are some examples of how attentiveness is tacitly interwoven with the medical *habitus*. Attentiveness may be given but not called attentiveness. One assistant physician explained that "we doctors have certain medical knowledge that others don't have, and that is why we should especially focus on that. Attention can also be given by nurses or by the patient's family members" [fieldwork notes]. However, as the previous descriptions show, that attention can have a beneficent meaning, but it is not simply good 'as such'. It is all about being attentive *in* the specific care relation that a caregiver may have with a patient. For example, some patients have told us [KK] that they feel very closely connected to their doctor, which could be the reason

for showing (part of) themselves to him or her. An attentive caregiver does not overlook this. That does not mean that one has to spend a lot of time on it; in the case of attentiveness it is often enough to let the patient know that his or her (implicit) expressions are being noticed. This seems to contradict the medical *habitus*, in which all things irrelevant for diagnosis or treatment are often considered unimportant; nevertheless it is what makes patients feel better. Perhaps this attentiveness as a way of swaying with the patient, or this 'letting come', may seem a lot easier to realise for doctors than for nurses, as doctors do not have to justify their work as often. However, nurses also manage to make space in which the patient can show him- or herself, and to be attentive to what is shown. Attentiveness can be very complicated, but it can also be given in very simple ways: it may be hidden in a question like "why are you frowning?".

It becomes clear that attention comes by *seeing* the other. At the same time, one can never see another person in his or her entirety; attention therefore always means reduction. What stands out, however, as a major finding of these data is that when a patient feels seen, or understood, the caregiver's attention is focused on what the patient wants it to be focused on. This means that patients benefit from *shared* attention. Furthermore, a caregiver may help a patient by being transparent about the issue on which the attention is focused. This softens the fact that attention can never be directed at everything at once. When the caregiver is more open and transparent about the gap between what is seen and what is focused on, the patient may more often experience receiving attention.

**Conclusion**

The previous descriptions and analyses shed light on attentiveness in the hospital care. Attentiveness in care is often dismissed as a bonus, something extra, or as something that one can be good at besides one's real work. This study shows that attention is part of the core business of medicine. However, attention has many facets, and not all of these are equally present in hospital care. It becomes clear that attentiveness only has its good meaning and effect if it is the right kind given at the right time. Otherwise an unsatisfied feeling remains. Caregivers frequently succeed in giving the proper attention, yet this is often done tacitly. Attention in its broad meaning is not easily accessible, and caregivers do not always refer to it as "attention". This calls for a more elaborate study of the way attentiveness works in the hospital. From the examples presented above the complexity of the phenomenon of attention is evident. Attentiveness may be embodied; it may be hidden in a small question; it may be experienced though not intended, or the other way around. Sometimes attention can be managed, but it will

always be characterised by a certain uncontrollable aspect. Our attention surpasses our own projects, and it surpasses the various techniques and practices by which our attentive behaviour is modelled. On the one hand, being attentive calls for constant exercise; on the other hand, remarkably it seems to be a 'gift'; something that just does or does not happen. Or, as Waldenfels (2004) puts it: "If there is any primary form of attention which plays its special role […] in the course of our life we must admit that it keeps certain features of a savage attention". *Habitus* comes to the fore as a useful instrument for studying attentiveness in hospital care. The question of how the medical *habitus* is related to attentiveness calls for further fieldwork. More research on attention is necessary, in which both the amount of data collection should be expanded and further steps should be taken to 'uncover' the data material. In this article a first preparatory study of the material is presented, which should be followed up by a thorough revision and comparison with other cases. Further study of attentiveness may correct the generally superficial perceptions of it. This way attentiveness can be described in its broad and important meaning, as it deserves, which may be a first step towards the giving and receiving of more attentive care. Hence, attentiveness no longer only speaks to the imagination; rather, its practical face is being painted.

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Background story 2:

# A WORKING DAY OF A RESIDENT DOCTOR

**Start: 7.45 a.m. in residents' room**

Coming from outside, the doctor changes clothes in the residents' space that consists of some shared rooms with lockers, and a place with sofas, table and television. He gets a cup of coffee and chats with colleagues while he puts on whites (long coat over regular clothes) and takes some notes and instruments from his locker which he puts into his pocket. Then he walks to the lecture hall where the radiology meeting takes place.

**Radiology meeting: 8.00 a.m.**

Every morning, all internists, residents and interns gather in the lecture hall, where a radiologist presents and explains all scan results. When an echo or scan is displayed on a large screen, the resident of the particular ward briefly reports for what purpose the scan is made. The radiologist explains what the scan shows.

**Morning meeting 8.15 a.m.**

After the radiology meeting, everyone walks to the transfer room behind the polyclinic. I ask one of the doctors why she was so busy last week. She replies that she had taken on an extra task because a colleague of hers had to attend a funeral. That day she was 'consultant', meaning that she could be called in for all problems with an internal nature for patients throughout the hospital. Combining that with the work on her own department proved to be quite stressful to her. 'But you do that, of course, when a colleague has a funeral', she adds.

Six internists, six residents and four interns are present. The specialists and the residents take a seat at the table. The interns are at the side against the wall. The doctor who has been on duty last night, provides information about the patients. One of the internists asks the interns a few questions and explains some things to them.

As I arrived late this morning, I am not wearing a white coat yet. One of the specialists asks me to explain who I am and what I am doing. This is quite interesting, because I have been walking around here for weeks and I have attended this meeting several times. He hasn't noticed me until now when I'm not wearing a white coat. He appears to be the only one who does not know who I am.

**Coffee: 8.45 a.m.**

As the morning meeting didn't take long, the residents have time for a coffee in the seat next to the residents' room. They talk about their colleague S. It turns out that all the residents agree that she's not functioning properly. Her colleagues are worried. They feel that the bosses (specialists) should have a chat with her, because it cannot go on like this. What is the problem? The residents give a whole bunch of examples: S. always asks 'what do you do with a patient who always...', and 'what do you always do with an IV...', and so on The doctors think those are not good questions, because most of the times there are no rules. 'Actually we don't work according to protocol that much', one of them says. S. also has quite a wordy way of expressing herself. She often calls her colleagues with a story without beginning or end. She has difficulty distinguishing major issues from minor ones. 'She doesn't have a good clinical eye.' 'She simply puts protocols and textbooks in her head. Her questions don't go beyond the overall picture, she does not know much to tell about cases in particular.' One doctor coughs. 'I think it's not right though', she says, 'everyone is talking about her behind her back, and she doesn't know.' They agree that the bosses have to take it up. But do the bosses see just how bad things are? Perhaps this is a task for the residents. 'Her contract will be extended!', someone remarks. Another concludes: 'I think it's really sad, I think she is aware of the fact that she is not in control of things, I think she feels quite insecure...'

**At the ward: 9.00 a.m. doctor's rounds**

We are at the ward and the resident is working on the computer. Then one of the oncologists comes in, asking 'Where is everybody?'. The doctors' rounds can begin, but she is still the only specialist at the ward. We go to the meeting room. I grab a chair and ask if I can sit there. 'Sure you can sit there', she says, surprised. 'You are the one that has to see it all here!', she laughs. A fellow oncologist also comes in, he runs straight through to the other side of the room and turns off the heating. He flaps his hands and pulls a flushed face. It is indeed warm in here. Then he takes a seat next to the ward doctor who operates the computer. He pours himself a coffee, notices the sugar bags are low, gets up, runs off and comes back with a handful of new bags. The first patient is being discussed when a third oncologist enters. There is not much more room to sit, and he grimaces. He does not arrange a seat but clumsily lingers until some people move closer together and create a place for him. All quite automatically.

The patients are discussed in order of room and bed number. The resident presents the case, then there is a discussion about the proposed policy. Once they have discussed all patients, the oncologists are to make a round along their patients together with the resident and a nurse.

But then chaos arises. One of the oncologists would like to discuss something with her colleague. In private, apparently. The third oncologist gets lost. The resident goes back to the doctors' room to answer a few questions from nurses that they have submitted through the computer system. Then he waits for the specialists in the hallway. When they finally start the round, I ask the doctors if I can join them. The oncologist replies: "Listen, four people is already a crowd, so it doesn`t matter if there's a fifth person." We visit the patients one by one.

Afterwards, the resident complains that it is always so messy during the doctor's rounds. The other oncologist used to visit a new patient alone. Now the resident has not seen him yet. 'This is quite inconvenient.' Then the beeper sounds. A patient with cancer arrived at the emergency department and she must be seen. The resident goes there immediately.

**Peer intervision, 1.00 p.m.**

All residents Internal are walking through the corridors of the hospital on their way to a conference room for peer intervision. 'That'll give you some time off', says one of the residents. 'Why? Can't I join you?', I ask. 'That's impossible', he answers. 'It is a rule that there is no one besides us. No interns either.' I ask if he has a problem with me being there. He doesn't, but these are the rules, he says. I ask the other doctors. They all say it's fine. I ask permission from the internist and psychologist who are in charge. The theme of this peer intervision meeting is dealing with families. One of the gastroenterology residents has prepared a case. The case is discussed, the psychologist offers advice, and experiences are shared.

'What a fuss they made about your attending the meeting!', a resident says on the way back. 'Do you think the topics they discussed were all that personal?' He explains that the doctors are faced with many more issues which are much more difficult. The other residents confirm that. I ask if there are other places they can go with that kind of stuff. No, there aren't. This peer intervision is the most 'profound' meeting there is. Occasionally they can have conversations with the residents' supervisor. However, these are often cancelled due to lack of time. Moreover, he does not like any fuss. He says that when he was a resident he had to work much harder than we have to, and in much poorer conditions.

I ask about the case prepared by the gastroenterology resident. I was under the impression that he, as a resident, had to do things that are done by the specialists here at oncology. The doctors explain that oncologists are indeed quite involved. They have all the family conversations themselves. Oncology is no lighthearted matter, they explain, that's why oncologists are more involved than other specialists. 'Surgery or cardiology residents may perfectly do a family conversation.' The residents talk about the Bergman clinic, which advertises

with 'Here you are never attended by a resident, but always by a specialist.' They laugh. One of the residents adds that she sometimes feels like oncologists are on the ward too much. '"They should have some faith in us. Why are we here otherwise?'

**2.00 p.m., ward**

The ward doctor is eating a sandwich behind his desk while he makes notes in patient records and answers questions from nurses on the computer. He resents how some nurses only take temperatures and don't do anything else. If you want to know more, then you have to ask particular questions. Occasionally, a nurse walks in to ask a question. The phone rings: the patient he saw in the Emergency Department is going from hypotensive to hypertensive'. He goes there immediately and stays for almost an hour. Back on the ward, he calls the gastroenterologist who has done an exploratory operation on one of the patients and found a tumor. This afternoon at 17.30, there will be a meeting with the family. The resident tells this by going to the nursing staff himself, so that they can inform the patient and the family. He then calls the pharmacy to ask if they can erase a particular medicine from a patient's list. The pharmacy lady replies that the nurses should do that themselves. The ward doctor is upset when he puts the phone down: 'It is ridiculous how some people keep passing the buck!'

At the end of the afternoon, the oncologist enters the room. He takes some cookies out of the jar, logs onto a computer and makes a note that everything is so nice and quiet. He had expected chaos because he thought there would not be any residents today due to a job application procedure. I think this is a compliment to the resident.

**4.45 p.m. weekend transfer**

A colleague calls the resident asking him to come to the meeting room for the weekend transfer, which is about his patients now. There are a number of internists, residents and interns. One of the doctors is reprimanded by a specialist for consulting a surgeon before analysing the outcome of a scan.

**5.15 p.m. inserted family conversation**

The ward doctor rushes over to the family conversation at the ward. Everyone is ready, the little parlor is packed.

**Ward: 6.15 p.m.**

We are back in the doctors' room. It is completely empty and dark. The resident sits down in his chair, his legs are on another chair. He takes a deep breath. The intern plops down in a chair as well. Finally, there is some time to talk. The resident says that when he gets home at night, his mind is still racing making him unable to hear anything his girlfriend says to him for an hour. He is now going to spend another half hour typing, making sure all has been reported in the patient records.

**Change clothes: 6.55 p.m.**

At 7.00 p.m. he leaves the hospital.

5

# THE COMPONENTS OF ATTENTIVENESS IN ONCOLOGY CARE

Klaver, K. & Baart, A. *The Qualitative Report;* forthcoming

**Abstract**

This article presents the first findings of a qualitative empirical study of caregivers' attentiveness in hospital oncology care. It takes a care ethical perspective, in which attentiveness is considered an indispensable element of good care. The data are derived from participant observation at the oncology department of a general hospital in the Netherlands. The analysis shows a descriptive exploratory model of attentiveness which comprises a coherent set of the clusters perception (A), object finding (B), and space for attentiveness (C). The methodological output of this article is an important one: the presented descriptive model of attentiveness promotes further research into the characteristics and functioning of attentiveness in care. It is a fundamental step towards a grounded theory as it enables a comparison of different cases prior to thematic analyses. The substantive outcomes of the study offers caregivers a tool for understanding and analyzing care practices from the perspective of attentiveness.

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# THE COMPONENTS OF ATTENTIVENESS IN ONCOLOGY CARE

## Introduction

From a care ethical perspective care and attentiveness are internally connected. To promote good care it is therefore essential to understand more of the hitherto poorly defined and little studied phenomenon of attention as an ethically relevant concept. Different authors have elaborated on the relationship between attentiveness and care (Engster, 2005; Conradi, 2001; Tronto, 2013), of which Tronto's analysis was the most influential. She distinguishes five phases of care, which are conceptually separate, but interconnected in practice. According to her, the first phase is *caring about*, which she links to the ethical element of attentiveness. *Caring about* implies that care is necessary. It means identifying a certain need and establishing that this need should be met. This will often involve assuming the position of another person or group in order to recognize the need. Attentiveness is described by Tronto as the quality of individuals to open up to the needs of others. This view is important, but it is too narrow. We argue in favour of a broader view, in which attentiveness is not only a first instrumental step in care, but also the core element of care and, as such, essential for the following steps as well and even a good in itself (Klaver & Baart, 2011a). Research into the experiences of care receivers suggests that they identify good care with recognition: care receivers value being seen (Van Heijst, 2011; Vosman & Baart, 2011; Wilken, 2010). Attentiveness can make a caregiver see what is at stake for someone and how they might be supported. This means that attentiveness and care are interrelated: without attentiveness good care cannot exist (Tronto, 2013; Conradi, 2001). This applies to oncology care in particular, where patients' diseases are often multi-causal and incurable, and complex and/or chronic or terminal. However, in studies on attentiveness in (oncology) care, attentiveness is in general addressed primitively, by equating it with empathy, concentration or proper treatment. It is regarded a bonus on the side, something that adds friendliness, empathy or humaneness to care that should essentially be technically competent (Klaver & Baart, 2011b). Care ethical studies though, do show that attentiveness, as an indispensable ingredient of attuning to the other

relationally, belongs to the core business of health care (2011). Despite the crucial importance ascribed to it, however, care ethical literature does not show any empirical studies of attentiveness, which is the starting point for this study.

In order to be sensitive to the broad and complex workings of attentiveness in care, we have let ourselves be nourished by insights on attentiveness from philosophy and phenomenology, psychology, theology, spirituality, and literature and art theories (Klaver & Baart, 2011a). In this intradisciplinary view, in which the focus is care ethical (Klaver, Baart & Van Elst, 2013), attentiveness can be understood as a social phenomenon that can exist between people. It is located at the intersection of attentiveness as a cognitive ability (Johnson & Proctor, 2004) and attentiveness is expressed as care or love (Conradi, 2001). Attentiveness can make the difference between an instrumental relationship between caregiver and receiver, and a relationship in which good care can be given. In the latter case, this can lead to what might be good for the patient and what the attentiveness should be focused on. In this relational perspective, attentiveness has two essential actors or actor groups: a giver (of attentiveness) and a receiver. Therefore, what is perceived as attentiveness by the caregiver may not always experienced like that by the patient (Tronto, 2013).

This article is based on a grounded theory study undertaken on a hospital oncology ward in the Netherlands. It describes how attentiveness appears in this particular care practice. In this article, we report the findings of this study by presenting a descriptive model of attentiveness. This descriptive model yields profit in two important ways. First, the model is constructed in order to enable constant comparison, which is a prerequisite for the intended grounded theory of attentiveness (Fram, 2013). This is an essential step in a grounded theory which is based on data from participant observation, but scholars do not often transparently elaborate on this intermediate step (Laitinen et al., 2014). Second, as the descriptive model on itself comprises the components of attentiveness, it provides caregivers with opportunities to analyze care situations from the perspective of attentiveness. It enables them to check which components of attentiveness are met in a particular situation and which are left out. The model thereby facilitates judgmental evaluations, without being judgmental itself, and contributes to ethical awareness and moral competence.

Both researchers have a background in social sciences and are skilled qualitative researchers. Besides, the researcher who collected the data has an education and work experience as a caregiver. However, beforehand she was unknown with the particular research setting, and therefore more "outsider" than "insider" (Corbin Dwyer & Buckle, 2009; Bonner & Tolhurst, 2003). The study arose from their affinity with and interest in the ethical aspects of (professional)

care. They share the mission to get grip on the often implicit things that make care good care, with the ultimate goal of making healthcare more humane. The first author is a young scholar who was introduced into the care ethical perspective some years ago. The second author, her supervisor, has been working in this field for a long time and has published earlier on the importance and meaning of attentiveness.

## Methods

### *Data collection*

Data were collected through participant observation with incidental conversational interviews. Participant observation was chosen because attentiveness is largely pre-reflexive and embodied. The main question of this study is not what the participants understand by attentiveness or how they voice this explicitly; it rather seeks to understand how attentiveness is acted out all the time and occurs in the experiences of those involved (Corbin & Strauss, 2015; Charmaz, 2006).

The study was performed in a general hospital in the Netherlands and was approved by the Institutional Review Board of the hospital. Participant observation was carried out on three divisions of the oncology department: the nursing ward, the outpatient basis, and the polyclinic. Participants were recruited through 'snowball sampling' (Green & Thorogood 2004). They were doctors and nurses. No distinction was made between differences in education and experience. The position as a researcher was made known to the participants under study. The focus of observation was on interactions in context between caregivers and patients, but the wider activities including meetings, peer consultations, and lunch breaks were also observed in order to gain an insight into the social and organizational structure of care. All handwritten observations were transcribed verbatim immediately. The researcher each time was a (half) day at one department and usually followed one caregiver at a time. This means that the researcher took on a white nurses' or doctors' coat and thereby took on the role of the doctor or nurse. This way, the researcher was not only able to observe what was visible, but also what was heard, felt, tasted, or smelled. Throughout the participant observation, the researcher asked questions to clarify what had been observed.

### *Data analysis*

The ultimate aim of this study is to formulate a theoretical model that explains how attentiveness works as it evolves from the empirical data. The study takes a grounded theory approach (Glaser & Strauss, 1967) as this method leads to the development of a theory. On the way towards understanding attentiveness in hospital care, theoretical concepts were developed during the research process, and there were no pre-formulated hypotheses. Throughout the analysis, the researchers wrote memos exploring their own perceptions, experiences, and existing knowledge, which were then constantly compared to other data. The researcher perspective is thus interwoven into the analysis. The two authors discussed every step of the analysis of the data in order to achieve peer validation.

The analysis of the data started with an immersion in the data - reading and re-reading the transcriptions, comparable to the heuristic approach according to Moustakas (1990). After this familiarization with the data as a whole, 22 units were selected. For the reason of exploration, this was done through diverse case selection to illuminate the full range of variation (Seawright & Gerring, 2008). The selection was also based on thick description (Ponterotto, 2006), or richness in terms of information (Creswell, 2003).

The first step of the analysis involved initial coding (Charmaz 2006). Essentially, each unit was read in search of the answer to the repeated question "What is this about? What is being referenced here?" We wrote interpretative case descriptions of the data. Then, we switched to focused coding (2006). For every case we answered the question: what is the problem to be solved and what is, or could have been, the significance or meaning of attentiveness here? In this stage, in which the comparison takes place within a small sample of cases, no uncommon or extreme cases were included (Seawright & Gerring, 2008). In order to enable a comparative analysis, the interpretative case descriptions were examined for their common elements. A data matrix was made of the 22 cases containing the tagging of properties into 24 main categories. These categories covered every example in all its specificity, and included:

- What is the reason for the contact?
- How familiar are the caregiver and the patient to each other?
- How does the caregiver perceive the patient?
- What is this image based on?
- What is the caregiver's substantial object of attention?
- Is there any movement or does the object remain the same?"
- How does the patient affect this?
- Which context factors play a role?"
- What is the result for the patient?

Subsequently, relations between all categories were identified and a model of core concepts that describe attentiveness was made, tested, and refined step-by-step until all categories were adequately linked.

After that, the analysis involved theoretical processes of coding (Charmaz 2006). The common elements, or description categories, were summarized in a descriptive standard model of attentiveness. This can best be described as a process of trial and error. It is likened to "decorating a room; you try it, step back, move a few things, step back again, try a serious reorganization, and so on" (Abbott 2004 *in Saldaña, 2009*: p.215). Analytic insights were tested against new ideas, the initial ordering of problems and concepts was refined, we compared it to other cases, and so on. We searched for categories that grasped the material, and refined or adjusted them until we found the best fit. We then inserted some new cases, apart from the first 22, and tested whether the descriptive model covered these adequately. This, again, was a search for the best fit: can we now describe attentiveness systematically, differentiated and according to a fixed but generally applicable standard? The final model could be standardized, as it allowed cases to be comparable. In this article we present this standard descriptive model of attentiveness. This is an essential step in constructing a grounded theory based on data from participant observation, but scholars do not often transparently elaborate on this intermediate step (Laitinen et al., 2014).

After this, but this falls outside the scope of this article, all cases were eventually described though this standard model. After that, analytical characteristics of being attentive were collected and clustered into patterns in a process of constant comparison. In the pattern-level analysis, respectively 16 types of attentiveness were identified. In any of these provisional types, a characteristic configuration of patterns was found. Those 16 types could be clustered further into 9 encompassing types, from which the main features were described and illustrated. These findings were presented in another article (Authors; *forthcoming*).

*Methodological discussion*

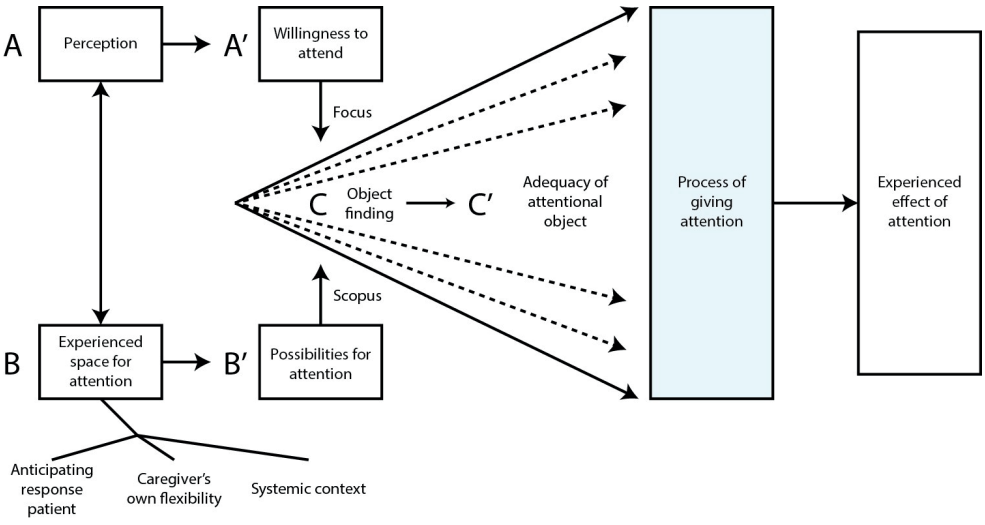
As announced earlier, this article shows a stage in the development of the grounded theory, which we have called a descriptive exploratory model. Why does this study present such a descriptive model, while many other studies using a grounded theory approach, skip this step? This is because the object of this study is 'attentiveness', although we still do not know what attentiveness is exactly. Actually, this is precisely one of the research questions. The data collection took place without the existence of a fixed idea or definition of attentiveness, which is

in line with the grounded theory approach. The researcher worked on the basis of sensitizing concepts for what attentiveness might mean (Anfara & Mertz, 2006; Bowen, 2006). The concept is deliberately kept broad and vague. While we assume the collected cases were about attentiveness, in order to allow for the comparison of the separate cases we must now first ensure that there is an agreement on the precise object and on the (working) definition of attention. Therefore, we have developed this model: a standardized descriptive model with which each observed situation that presumably has something to do with attentiveness, can be described based on the same categories. This way the case descriptions become comparable to each other, allowing for similarities and differences to emerge and patterns to be detected.

## Results

The analysis of the data shows that attentiveness can be understood as a coherent set of various categories which can be categorized into the following interacting core concepts: perception, experienced space for attentiveness, and object finding. The negotiation of these concepts gives rise to a process of attentiveness, ending in the outcome of attentiveness experienced by the patient. See also figure 1. In this article, we focus on the components of attentiveness, i.e. the part that is about being attentive.

**Figure 1**. Coherent set of clusters: descriptive model of attentiveness



Perception (A) covers the caregiver's perception of the patient. It contains both perceiving *facts*, i.e. the cognitive processing and interpretation of what someone says, means and thinks, and perceiving *emotions*. This leads to a certain willingness to attend (A'), implying a practical as well as an emotional and a moral willingness.

Experienced space for attentiveness (B) is about the struggle to be able to be attentive. It is firstly about anticipating to the patient, such as wondering how far one can go and what things should the caregiver stay away from. Secondly, it contains finding space in yourself, meaning asking questions like whether you are strong enough to do something. Thirdly, the experienced space depends on the systemic context or the institutional organization of the care containing issues like rules, protocols, professional expectations, collegiality, and so on. These factors culminate in possibilities for attentiveness (B').

The cluster "object finding" (C) is a central figure in the model. It is about finding an answer to the following question (although this often happens preconsciously): "What am I actually looking at?" "Do I understand what is demanded from me?". This finding of the object of attention leads to (a certain degree of) adequacy of the attentional object, adequate from the patient's perspective (C'). Through, for example, processes of divergence it may occur that an object is determined that is inadequate, because the expectations of the patient and the actual attentiveness of the care provider differ. Now that we have distinguished these components of attentiveness, we can indicate several trajectories that seem to be crucial when it comes to the way patients experience attentiveness.

*Perception*

Forming a picture of the patient and what is at stake for him or her is done primarily on the basis of what the caregiver perceives. This is strongly influenced by the way patients express themselves. Some patients know exactly what they want and express this explicitly in the form of a clear request:

> Ms. D. has a thick left arm which is encased in a tight stocking. She calls the nurse to say she has such pain in the skin on her chest. Her left breast was amputated and the operation left a scar, the skin is very dry and tight. She feels that it may need some cream be rubbed on, but she cannot do this herself.

Others are very cumbersome in transferring what they would benefit from, or they do not even know that themselves.

> Chris is nearly 80 and his file says he functions at the level of a 3-year-old. Plaintive moans come from his room: Chris cries. The nurse enters his room, sees his teddy bear lying on the ground, picks it up and gives it to him. Then she says "Now it's good eh!". I think, yes? (Chris still cries). Then she asks: "Is that good? Are you ok?" But there is no response, Chris continues to cry. The nurse shrugs, looks at me questioningly, and then leaves the room.

Apparently, caregivers cannot always immediately see what is going on. There is more than just the direct perception. Since forms of interpretation are also part of the perception, we must not forget that the caregiver may draw from other sources when imaging what is at stake for a patient, such as his memory, expectations or beliefs.

> The nurse inspects the scar. The skin is tight and there are some small flakes on it. It looks like it could really use some cream. I give the bottle to the nurse and she rubs the skin. She does this without gloves. She asks if it hurts, but Mrs. E. says she has a high pain threshold. Ms. E. has a friendly face with wide cheekbones. Her head was bald but now, some thin soft hair is growing there again. She has trendy fifties style glasses. Her pajamas look expensive. She looks well cared for, despite being ill: blue eye shadow, pink lipstick. Her eyebrows have fallen out due to the chemo, but she has signed lines with a brown pencil. Sometimes she looks at me and gives me a friendly smile. I do not feel uncomfortable. I do not get the feeling that Mrs. E. finds it annoying that I am watching them. The nurse rubs with care, and gently massages it until all white cream has disappeared. I realize this rubbing is not just rubbing, but it is done with an eye for possible shame and pain. This is based on previous experiences with patients who had undergone a mastectomy, but also on their own experiences of being a woman, of needing care, of undressing in front of others, and so on.

The image of the patient may vary from a multifaceted picture to a simple sketch. In certain cases, the image does not reach beyond the medical image, making it impossible to bring about an attentiveness that includes the person. This is often very logical and understandable, for example when an emergency situation forces a caregiver to concentrate on fighting physical danger. More often though, the picture is expanded with details of different natures: the image may include personal characteristics of the patient, details about their emotions, about what their life is about, and so on. The occurring image is not static: it may narrow or widen depending on purpose and context. This is reflected in the way patients are discussed in doctors meetings:

> Mr. H. (64) is operated by the urologist. He has abscesses in the surgical area. He has a recto fistula and he pees pus. The urologist does not want to come by on this oncology ward, says the physician assistant.
> Physician1: "We are really just doing post-operative care for the surgeon which is nasty..."
> Physician2: "I suddenly remember that I had his brother as a patient a few years ago.
> His brother had the same disease..." [He gives his colleague a questioning look]

> Physician1: "Could be..."
> Physician2: "His brother passed away here in the hospital that time, or no, no, he just got home, I believe. So that family is now going through exactly the same misery as then..."

It also matters to what extent the image is specific to this patient. In some cases, it seems that the caregiver's image of the patient is mainly based on his general knowledge about people, or patients, or cancer patients, more specifically. Sometimes, the attentiveness is influenced by the caregiver's personal opinion on the patient, finding them sympathetic, for example.

> On a deeper level of explanation and understanding we see a specialist who does her very best. This is noticed by the way she approaches the patient and her partner, how she acts, what she does first and what later, attention to detail, and so on. Presumably, her commitment is also so great because she likes this couple. Not only do they share the same sense of humor and type of appearance (haircut, clothing, diction, hobbies) but the doctor and the couple also are fully fledged partners. They have even worked in healthcare. There is a large degree of reciprocity: the patients are attentive and helpful to the specialist and the other way around.

Evidently, the caregiver's imaging of the patient influences the occurring attentiveness, as it leads to a certain willingness to attend. However, it is not only about this image and willingness; attentiveness also depends on other circumstances. The influence of these circumstances is discussed in the next section.

*Experienced space for attentiveness*

The research data show that the space for attentiveness experienced by the caregiver is constrained by at least three sources: the patient, the caregiver himself and the systemic context. These forms of space definition will now be discussed.

Firstly, it is not always true that patients benefit from caregivers attending to what is at stake for them. In many cases, the attention had better focus on a just part of what matters, rather than to all of it, and sometimes even better on something else. The simplest example is when a medically acute situation occurs: whatever the patient may go through at that moment (e.g., agony), the caregiver should only focus on fighting the disease or any other physical danger. Other things that might possibly be better to ignore are, for instance, a patient's personal issues that they don't want to be addressed by the caregiver.

The second factor defining the space for attentiveness is the flexibility of the caregiver himself. Sometimes attentiveness requires caregivers to cross their own boundaries. It takes courage to really face someone who feels miserable, and not to close your eyes, or stop feeling. A

caregiver may start feeling insecure because he thinks that an appropriate response is expected of him, while he has no experience with such major issues.

> Mrs. R. must unexpectedly undergo a rectal examination. She is quite overwhelmed, as she likes to keep control. When the investigation is finished, (the doctor says he has found nothing strange) Mrs. R. says "I'll tell you one thing: giving birth is easier than this!" "Really?? Was it that bad?", the doctor cries out surprised. "Terrible", Mrs. R. replies. The doctor leaves the room. He is in shock: Mrs. R. has told him this now and he hadn't noticed it. He looks startled.

It also occurs that they don't want to be confronted with the misery of a patient, because it reminds them too much of sad things that they experienced themselves. Furthermore, it is frequently required to oppose a colleague or a superior in the interest of the patient, while the caregiver doesn't actually have the courage to do this.

> Along with the nurse I walk over to Mr. B. He has suddenly broken his arm this morning and has many questions about how to move, what to pay attention to, whether he should stay in bed, etc. The nurse stresses that this could have happened at any time, because he is so fragile, it can hardly be avoided (later she tells me: there is probably another tumor in his arm). Then the physician-assistant enters the room; she has seen the X-ray. The arm is broken indeed, and now the surgeon must decide what the best option is. The doctor says that she had already called the surgeon, but she was told that it is 'not desirable' for an assistant to do so. She must now wait until she can discuss it with the oncologist, so that he can discuss with surgery. Meanwhile, Mr. B. and his family are in uncertainty.

Emotions may also be impeded when a caregiver dislikes a patient. Being attentive for caregivers often means discovering their personal limits.

The systemic context also affects the experience of space for attention. Caregivers are not "free" to focus their attention on whatever occurs. Attention is always given from a certain position and in a certain context. A doctor and a nurse have similar points of attention, but they may also look at very different things in the same situation. The appearance of attentiveness in health care is related to the structural context in which the care is given. The profession of the caregiver, the organization of the department, and various protocols and rules expect certain things of caregivers.

*Object finding*

The interaction between perception and experienced space for attentiveness defines the space in which the attention can be focused. The caregiver has an idea of what is at stake for the patient

and he feels a certain space to attend to this. This finding of the object of attention leads to a certain degree of adequacy of the attentional object from the perspective of the patient. Through processes of divergence it may happen that an object is determined that is inadequate from the perspective of the patient, because the expectations of the patient and the actual attention of the care provider differ. This difference arise when a caregiver focuses on the medical image while denying the lived experience of the patient.

> Mrs. J. is a patient who feels ill but "objectively, she is doing fine", the doctors say. She lies in bed. On her lips are dark crusts. SO1 gives her a hand. He begins by summarizing the situation: all results are good, catheter was taken out yesterday.
> Pt: "I am short of breath, doctor."
> SO1: "Yes, the body has had a lot to suffer!"
> Pt: "The pain doesn't get less."
> SO1: "Yes ... yes ... but your body needs time to recover, you know, it takes up to six weeks before you're all over it."
> Pt: "No, two weeks, right ??"
> SO1: "Six." [pause] "So, how are you doing further?"
> Pt: "Well, if the results are good it will be good, but it is still hard, doctor."
> SO1: "You will feel better soon."
> Pt: "Okay, doctor"
> SO1: "Okay. Yes. Then we'll try it this way. Yes. Good. Goodbye, Mrs. Jansen!"
> [He shakes her hand. The assistant does as well. Mrs. Jansen jumps at feeling his cold hand. They all laugh.]

It may also consist of the difference between the focus on a device versus a living person, or on a small aspect versus the bigger picture. This seems to suggest that the patient's experience is only positive when there is convergence regarding the attentional object, or, in other words, when the caregiver's attention is focused on the same object as the patient's. But this is not always true. In some cases, a caregiver focusing on a different object can be more beneficial to a patient.

> This patient has a cervical carcinoma and chemotherapy is given in combination with radiotherapy. The oncologist visits her at the policlinic where she undergoes the chemotherapy. She tells him her whole 'underside' is scorched by the radiation treatment; her whole is open and damaged. Soon they will also start internal radiotherapy, which will make it even worse. She uses a cream from the drugstore and has lots of pain urinating. The doctor prescribes an anesthetic cream. He also says "drinking a lot, that's the only thing that helps!", but that is a huge mistake because the woman should instead drink as little as possible because of comorbid heart failure. The woman also indicates having an infection in her armpit. The doctor looks at it: it is a large reddish brown spot with a gauze pad completely drenched in pus. When he touches it the lady cries out in pain. The oncologist will ask someone from surgery to look at it: "You should not let me do this, I can't", he tells her.

The finding of an object is not a static, single event but rather an ongoing, dynamic process.

Once the space for attentiveness has been identified and settled, signs occurring outside this area are usually not perceived. However, within the predefined space, new signs can occur that may be noticed and focused on. Caregivers often seem to look slightly next to their original focus and sometimes we will find them focusing on a completely different object after a while. As described earlier, these objects are no fixed things, but interpretations thereof. Arvidson (2006) makes a distinction between attentional capture and contextual capture. In attentional capture, a theme, such as hearing your name aloud, causes you to turn around to attend to this new theme. In contextual capture, one context is replaced by another that sees, for example, the patient as a full person. Or, in a lesser attentional transformation, the context is elucidated in a way that brings out, for example, the humanity of the patient. In the case of elucidation, what is unclear gets clarified, what is also relevant but obscured becomes more apparent as contextual. For example, that healing a person involves a person and not just a mechanical thing to fix. The process of object finding can be understood as a learning process, characterized by motion, dynamics and flexibility.

**Discussion**

In this article we aimed to explore how attentiveness appears in hospital care. This is the first empirical study departing from a care ethical perspective and using a broad, intradisciplinary conceptualization of attentiveness. Our analysis identified a coherent set of various aspects which can be categorized into the following interacting clusters: A) perception, B) experienced space for attentiveness, and C) object finding.

Perception is understood as the process of forming a picture of the patient and what is at stake for him or her and we have shown the variations when it comes to these images. Many phenomenological studies have shown that perception is related to attentiveness (Arvidson, 2013; Steinbock, 2004; Waldenfels, 2010). The issue of interpretation and understanding is often described when it comes to the diagnostic work of doctors and nurses (Evans, 2012; Malterud, 2001). The current study adds to these insights that similar mechanisms play a role when it comes to attentiveness wider than the clinical gaze or the intention to diagnose. Specifically, the findings show that a caregiver's personal expectations, beliefs, and opinions on the patient influence the attentiveness that will be experienced by the patient. This is in line with findings in e.g. spiritual care, where the "personal factor" is decisive for the quality of care (Leeuwen, Tiesinga, Post & Jochemsen, 2006). This finding is important especially given that many forms of medical and care education try to leave out of consideration the personal influence of the specific caregiver as

much as possible, because it is considered to be an inhibition of good care, rather than a constitutive condition of it, (Evans & McNaughton, 2010; May & Alnst, 2006; Crehan, 2002). Besides, the majority of criteria on quality of care are not about *good* care, but about *accountable* care (Epstein et al., 2014; McClellan et al., 2010), which inherently displaces the personality of the specific caregiver to the background. This study underlines the importance of integrating the person of the caregiver into thinking about quality of care, as the findings show that the attentiveness of caregivers is influenced by their own personal emotions, beliefs and opinions. This also confirms that, for a thorough understanding of attentiveness in care practices, it is not sufficient to turn to the neuropsychological models of attention (Posner, 2012; Petersen & Posner, 2012). These models were not developed on the basis of research into care practices anyway, and they are often used to assess an individual's ability to perform an attentional shift and, as such, may be relevant. However, although a caregiver's attentiveness to patients to a certain degree may be dependent on this ability, it fails to grasp the actual working of attentiveness in care. This is because a caregiver may score very high on attention in this model and still be completely inattentive to a particular patient. The neuropsychological models of attention don't take the moral aspects of attention into account either. In the broad understanding of attention that is used in our study, attention has morally relevant moments such as responding to a tacit appeal or not, recognizing an unarticulated desire or not. As attentiveness is the core of care and all care is morally loaded, attentiveness has a share in that moral venture. Arvidson (2006) uses the work of Buber when explaining what happens when attention becomes focused on some*one* rather than some*thing*. He calls this "moral attention," by which he means that another person has some special relevance to the subject. This does not only mean that it has a practical or emotional relevance, in the sense that someone, for example, uses someone else, or appreciates or pities them; in moral attention, the relevance between the theme, or object, of the attention and the context must be such that the other (i.e., the patient) becomes the object within the context of the ongoing attentive life of the subject (i.e., the caregiver). This is what we mean when we say that another person matters to you: You are directly relevant to me. This "compassion" - literally "standing together" - is a special principle of relevance for attention (Arvidson, 2006).

The results also show that caregivers often find they must cross their personal boundaries in order to give good care. This also comes to the fore in research on emotional labour (Larson & Yao, 2005). The systemic context is another factor constraining caregivers' attentiveness. The profession of the caregiver, the organization of the department, and various protocols and rules expect certain things are expected from caregivers and that they are not "free" to be attentive to

whatever occurs. The constant negotiation between what seems ethically good and the space there is to act accordingly, is consistent with the literature on moral distress (Gallagher, 2010; Gutierrez, 2005), which occurs when caregivers cannot do what they think is right.

Furthermore, the methodological output of this article is important. The presented descriptive model of attentiveness enables further research into the characteristics and functioning of attentiveness in care. It is a fundamental step towards a grounded theory as it enables comparison of different cases, which precedes thematic analyses. In addition, the article contributes to the describability of attentiveness in terms that are relevant for the ethics of care.

This study provides an insight into caregivers' attentiveness in hospital oncology care.

Nonetheless, there is a limitation that need to be discussed. Although qualitative methods score high on internal validity and in general accurately document the phenomenon studied (Pope, Van Royen & Baker, 2002; Starks & Brown Trinidad, 2007), there is one important limitation, which refers to generalizability. The data collection was limited to one oncology department that is located in a general hospital in the Netherlands. Oncology is a specific department, at which caregivers generally seem to be more attentive to patients' experiences than e.g. at orthopedic departments. We suggest that certain patterns are tenable to other departments and other countries, but that some other mechanisms would change. This, however, is an issue for future research.

The current study has first and foremost relevance for oncology care practice, as the disclosure of attentiveness and its components provides caregivers with opportunities to understand and analyze care practices from the perspective of attentiveness. This enables them to check which components of attentiveness are met in a particular situation and which are left out. The model thereby facilitates judgmental evaluations - without being judgmental itself - and thereby contributes to their ethical awareness and moral competence (Winston, 2012; Reynolds, 2008; Jormsri, Kunaviktikul, Ketefian & Chaowalit, 2005; Tronto, 1993). It may also help oncology caregivers to express empathy and to build rapport within the tight time constraints of a hospital.

The findings presented in this study underline the importance of looking at attentiveness when it comes to the evaluation of quality of care. There is a lack of indicators and criteria that enable a sharp picture of the caring side of health provision (Lepnurm, Dobson, Voigts, Lissel & Stamler, 2012; Watson, 2009; Council for Public Health and Healthcare, 2006). Such indicators often remain hidden in contemporary approaches to quality of care, but nevertheless, they seem to be highly relevant from the perspective of patients. Gaining an insight into the components of attentiveness may reduce this problem.

The exploratory, descriptive model that emerged from the initial data matrix has proved successful. We recommend the use of this model to study attentiveness in care because it ensures the relevant information from the data material is revealed. The model enables the comparison of different practical cases about attentiveness. More research on this topic is necessary in which both the amount of data examples should be expanded and further analytic steps should be taken to uncover the various aspects and trajectories within the components of attentiveness, in order to develop a grounded theory. The current study provides the building blocks for such a follow-up. Additionally, attentiveness in this conceptualization has important ethical implications. In this article, a first descriptive analysis of the data material is presented which touches on these moral aspects of attentiveness. In order to fully understand the ethical sides of attentiveness this should be followed up by a thorough (care-)ethical analysis.

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Background story 3:

# A WORKING DAY OF A NURSE AT THE WARD

**Start: 7.10 a.m. in dressing room**

The nurse changes clothes. She puts her own clothes in a locker and takes on a white uniform which she took from the cloak room downstairs.

**7.15 a.m. in nurses' room at the ward**

The day begins with a short gathering in which the nurses of the nightshift provide the day nurses with the details of the patients. The day nurses look fresh and bright. They drink coffee while the night nurses feel tired and cold. They wear warm fleece jackets over their uniforms. They share information about the patients, like how they have slept and certain difficulties and practicalities.

**7.30 a.m. Reading patient files, nurses' room**

The nurse takes a computer (on wheels) and starts reading. In room 1 lies Mrs. Finches, born in 1939. She has colon carcinoma with liver metastases. She takes Haldol, and if necessary morphine. There are no more treatment options for Mrs. Finches and her health deteriorates rapidly. Yesterday, she was administered the last sacraments. The family is sitting up by her bedside. Mrs. Dexter is in bed 2-1. She has breast cancer and a pain in her left arm. As she has just stopped the chemotherapy, the nurses must still be careful with her excreta (as these may contain toxic substances). In bed 2-2 lies Mrs. Oak from 1964. She has cervical cancer and receives chemotherapy. She was admitted to the hospital with 'general malaise', it didn't work out at home. She has bowel problems, takes Movicolon, and when it's necessary the give her an enema. This past weekend she went home. Bed 2-3 is Mr. Nan's. 'General malaise with pancreatic cancer', it says in the file. Sore back. Broken left arm. Bed 2-4 is Mr. Knight (1941). 'Rectal bleeding after removal polyp.' He is under the care of a gastroenterologist and can go home today. I ask whether Mrs. Cabbage is still there: she passed away yesterday.

**7:45 a.m. Goodmorning to the patients**

The nurse fills in our names on the notice board in the corridor. Meanwhile, she discusses the patients with her colleague (who has also read the files). Then she asks what her student nurse wants to learn today. He says he would like to arrange everything for the discharge of Mr. Knight. And he says that his supervisor told him to go through all the patients more often with the nurses he works with, so they can see that he keeps the overview. The nurse replies: 'Does your supervisor want that or do you want it yourself?' The student answers that he knows he keeps the overview, but he needs to show it more. Ok, let's get started. The nurse enters room 2. She calmly looks around. 'Goodmorning, how are you all here?' The nurse introduces herself to all patients but one (who is asleep).

**8.00 a.m. Patient care**

In room 2, the nurse hands out the medication pills. 'Shall I dissolve the Movicolon?' she asks Mrs. Oak. Meanwhile, the student does the checks (temperature, blood pressure, pulse). I open the curtains.

In every room there is a sink block with a faucet, which has cabinets underneath. I thought the sink was part of the adjacent bed, but it is communal: there are sheets, pillowcases, towels, washcloths, gloves, and there are some pumps with soap and disinfectant.

Some beds must be made while patients are away to wash. I assist the student nurse. Meanwhile, I ask him about his training. He will move over to the children's ward next month and afterwards to the pulmonary department. He previously worked in neurosurgery and surgery, which he liked more than the current ward. 'I have respect for the people who work here, but it's not my favorite department.' He believes that the work here is mainly about emotional support and you are judged on your interaction with patients. As far the medical side of it is concerned, he does not find it that interesting. 'There are a lot nursing home patients here, and that's not my population.'

Some patients ask for help. Then, Mrs. Finches (the terminal patient) needs to get washed. 'Not extensively', the nurse explains, but she must be freshened up. It doesn't matter for the patient, but the nurse does it particularly for the family. 'It is depressing when your loved one is dying and stinks as well.'

As we sit at a desk, the nurse shows me how to adjust the nursing plan. She feels that the nurses take too little work from that plan. If everything had a standard place in there, then you just had to report exceptions. Now, often texts are written such as 'The patient has had her medication', and that's not really necessary.

The relatives of Mrs. Finches regularly come over to let them know the oxygen in the nose is gone again. In the beginning, the nurse would go over to the room to put the thing in place, but later she says 'let's just try without oxygen for a while. I feel that the oxygen mask is more stressful than beneficial at the moment. Let's see how it goes, we can always replace it later.' Some other family members have arrived. The nurse asks if they want coffee. 'Yes, please, we could use something strong.'

An intern makes the visit today. She asks the nurse if she can come over to make a report. We take a computer and put it in the doctors room. We take a seat by the window, the intern at the computer, the nurse with a mobile computer next to it. The nurse reports about the patients, the intern asks questions.

The nurse stands in the hallway when a patient from the other side of the ward comes to her. She says she hates being in a room with a man who is constantly coughing and vomiting. He may go home tonight, but she does not understand. 'Can't they do something for him before he goes home?'

A fellow nurse is fed up with her computer. She was on vacation and cannot log in because her password expired during the holidays.

The nurse goes back to have a look in room 1, with Mrs. Finches. She has a chat with the family members who have just arrived and she explains to them what to expect now.

The hallway is being vacuumed and you can smell that typical vacuum cleaner air.

Before we eat, the nurses discuss all five patients.

**12.00 a.m. lunch**

The nurse and four colleagues have lunch at the hospital restaurant. They finish it having a coffee at the ward in the nurses' room.

**12.45 a.m. back to work**

Back to work. The nurses who are now off to have lunch, do the patient handover. It is very noisy behind the counter.

**2.50 p.m. Everyone is back from lunch**

The nurses gather at the computer. They report on what has happened.

The door to room 6 closes with a bang. 'That happens sometimes', the nurse simply says, and she opens it again.

Patients ask for blankets, a vase for flowers or some explanation. The nurse orders a new mattress for Mrs. Finches, as she suffers from serious bedsores.

**3.30 p.m. Drinks and finishing up**

'Who wants to have to drink?' a nurse hollers from the other side of the ward. We go to the nurses' room, where lemonade is served.

After finishing the drinks, there is a short patient handover to the evening shift, and then the nurse says goodbye to the patients.

**Change clothes: 4.25 p.m.**

At 4.30 the nurses leave the hospital.

# 6

# MANAGING SOCIO-INSTITUTIONAL ENCLOSURE

## A grounded theory of caregivers' attentiveness in hospital oncology care

*Under review*

**Abstract**

Caregivers' attentiveness is vital for healthcare quality, yet existing research lacks a specific definition and neglects its different forms and aspects. This paper presents a qualitative, grounded theory for studying how attentiveness appears in hospital oncology care. Our data show nine types of attentiveness. We answer the question why a caregiver practices one type of attention in a certain situation, and not another type. First, it appears to be of crucial importance whether attentiveness is essential for giving care in the opinion of the caregiver. Second, the focus of attention is essential. Care given by doctors and nurses is always ambivalent; on the one hand, it concerns the body, and on the other hand, it involves the person whom that body belongs to. What is the caregiver (mainly) focused on? The significance of socio-institutional enclosure emerged as a key theme within the findings. This concerns the space a caregiver may or may not experience to break free from the preponderant institutional orientation towards the physical body of the patient. At the intersection of the influence of socio-institutional enclosure and the substance of the caregivers' concepts of care, three cultures are found that comprise the different types of attentiveness.

# 6

# MANAGING SOCIO-INSTITUTIONAL ENCLOSURE

## A grounded theory of caregivers' attentiveness in hospital oncology care

**Introduction**

Attentiveness in care is often dismissed as a bonus, something extra, or as something that one can be good at besides one's real work. Care ethicists however have shown that attention is part of the core business of medicine (Author 2011). Attentiveness, or attention, has been defined as the quality of individuals to open themselves for the needs of others. Attentiveness meaning the noting of the existence of a need by assuming the position of another person, is seen as the first step to care, which should be followed by a responsibility to respond to this need (Tronto 1993). Ethics of care researchers such as Conradi (2003), Author (2004), and Authors (2011) emphasize the recognizing meaning of attentiveness. Being attentive does not only have an instrumental function in care (to find out what is needed), but it can also have a good effect on itself. Research has shown (Evans 2012, Cole-King & Gilbert 2014) that in order to provide good care - that is good care in the experience of the patient - open attentiveness is of crucial importance. The attention of the caregiver should not always be focused on something functional (i.e. on the diagnosis). At times, care benefits from attentiveness just for the sake of attentiveness because it can create a relationship in which the patient may express himself. It is clear that being attentive is not a matter of individual caregivers but rather depends on several different factors in health care (Iles 2014), and that it has important implications for the care patients receive. However, as attentiveness is often done tacitly or pre-reflexively, it is not easily accessible, and caregivers do not always refer to it as attentiveness (Author 2011). To date there has been no published literature on empirical studies of this conceptualization of attentiveness in health care practices. This qualitative study was conducted to address this gap.

## Methods

The aim of this study is to formulate a theory that describes attentiveness and its categories and properties as these unfold from the empirical data. This paper presents a Grounded Theory analysis (Glaser & Straus 1967) of field notes conducted on an Oncology Department of a general hospital in The Netherlands. In grounded theory, theoretical concepts are developed during the research process, and there are no pre-formulated hypotheses. However, many scholars have questioned whether researchers can conduct grounded theory studies free from bias or preconceived thoughts (Miles & Huberman 1994; Charmaz 2006). We followed the qualitative strategy of "sensitizing concepts" (Bowen 2006) or a "theoretical lens" (Charmaz 2006). In this regard, the current study invokes a care ethical perspective as a way to organize themes in a coding framework. As a central tenet of care, the care ethical perspective involves understanding the relatedness of human beings. Furthermore, it recognizes situatedness and contextuality, and it is a political ethical discipline which means that it looks at the relationships between power and caring practices (Author 2014). This framework particularly suits the complexities of care practices.

This study aimed at gradually working out a theory that provides an understanding of attentiveness in hospital care. Although it is debated widely, we agree with Glaser (2000) that the purpose of grounded theory is not to tell participants' stories, but rather to identify and explain conceptually an ongoing behaviour that seeks to resolve an important concern. Essentially, the findings of a grounded theory study are not about people, but about the patterns of behaviour in which people engage. The main concern conceptualised in the grounded theory may not have been voiced explicitly by participants, but instead abstracted from the data in which the concern was acted out all the time (Glaser 1998). Characteristic of the approach is the use of the method of constant comparison.

Throughout this study, the researchers wrote several memos exploring their own perceptions, experiences, and existing knowledge which were then constantly compared with other data. The researcher perspective is thus interwoven into the analysis. The researchers were both trained as social scientists. Their training as researchers lies outside of a clinical setting. Every step of the analysis of the data was discussed by the two authors in order to achieve peer validation. The study was performed in a general hospital in the Netherlands and was approved by the Institutional Review Board of the hospital.

**Data collection**

Participant observation was carried out on the nursing ward, the outpatient basis, and the polyclinic of the Oncology Department. Participant observation was used because the main question of this study is not what participants understand by attentiveness or how they voice this explicitly; it rather seeks to understand how attentiveness is acted out all the time and occurs in the experiences of those involved (Charmaz 2006). Because attentiveness is largely pre-reflexive and embodied, we have chosen for the method of participant observation with incidental conversational interviews.

Snowball sampling was used to recruit caregivers (especially doctors and nurses) and patients willing to participate in the study. The position as a researcher was made known to the participants under study. The focus of observation was on interactions in context between caregivers and patients, but the wider activities including meetings, peer consultations, and lunch breaks were also observed to gain insight into the social and organizational structure of care. All handwritten observations were immediately transcribed verbatim. The researcher each time observed a (half) day at one department and usually followed one caregiver at a time.

**Data analysis**

Data for analysis included transcripts of observations and informal conversations. The transcripts were coded in the software program Atlas.ti (version 6.2) using a Grounded Theory approach (Charmaz 2006). Grounded Theory methods are designed to discover theory within textual data. In this study, after familiarization with the data as a whole, 22 cases were selected for comparison. This was not done all at once as data were collected and analyzed simultaneously. In a later stadium, a form of theoretical sampling was used in order to compare the data to more data to (dis)confirm the insights regarding the most salient themes and categories that emerged from the earlier analysis. However, in a typical grounded theory, the researchers go back to the field and collect new data in order to allow for theoretical sampling. We did not go back to the field: we based our theoretical sampling on "unused data" we already collected.

The first step of the analysis involved initial coding (Charmaz 2006). We wrote interpretative case descriptions of the data. Then, we switched to focused coding (ibid.). In order to enable a comparative analysis, the interpretative case descriptions were examined for their common elements. After that, the analysis involved theoretical processes of coding (ibid.). The common elements, or description categories, were summarized in a descriptive standard model of

attentiveness. This model makes it possible to describe being attentive adequately on the basis of inductive and free descriptions, through which the different cases of being attentive become mutually comparable[12]. All cases were eventually described though this standard model. After that, analytical characteristics of being attentive were collected and clustered into patterns in a process of constant comparison. In the pattern-level analysis, respectively 16 types of attentiveness were identified. In any of these provisional types, a characteristic configuration of patterns was found. Those 16 types could be clustered further into 9 encompassing types, from which the main features were described and illustrated.

## Findings

*Managing socio-institutional enclosure - the theory*

Caregivers are not free to focus their attention. It is clear that being attentive is not a matter of individual caregivers but rather depends on several different factors in health care (Iles 2014). Why does a caregiver practice one type of attention in a certain situation, and not another type?

Managing socio-institutional enclosure was the central process identified during analysis of the qualitative data. This concerns the space a caregiver may or may not experience to come loose from the preponderant institutional orientation towards the physical body of the patient. The socio-institutional enclosure is on the subjective side strongly influenced by the caregiver's specific concept of care. Distinctive is whether this concept is inclusive or exclusive, i.e. including the person of the care receiver or not. At the intersections of the influence of socio-institutional enclosure and the substance of the concepts of care, three cultures are found that comprise the different types of attentiveness.

*Practices of attentiveness*

The analysis of the data gradually got at a higher level of aggregation: from individual descriptions to patterns of sub-actions, from there to complete, cohesive types, and so to large clusters of related types of attentiveness. In this study, attentiveness is considered a practice rather than an act. Attention is given in a very complex set of powerful factors, things, rules, logic, people, etc., and not as freely arranged acts, not even as a configuration of individual acts. Therefore, interpretations are on the level of practices and should therefore relate to the complexities of such situated, institutionalized practices that can only be entered through professional socialization.

[12] This standard model was presented in another article (Klaver & Baart; forthcoming)

In this extremely complex configuration of forces, emergent properties (Johnson 2006; Sawyer 2003) are involved. They can be thought of as unexpected behaviours that stem from interaction between de components of attentiveness and their environment. Although attentiveness can be understood to a large extent, there is always an escaping moment. Many factors can be explained but at the same time attentiveness will always be characterised by a certain uncontrollable aspect. Our attention surpasses our own projects, and it surpasses the various techniques and practices by which our attentive behaviour is modelled. On the one hand, being attentive calls for constant exercise; on the other hand, remarkably it seems to be an 'event'; something that just does or does not happen. Attentiveness has to do with a layered causality and for the analysis of the data this implies that a certain irreducibility and unpredictability is to be included. In the occurrence of specific types of attentiveness, the concept of emergence works as a reservation, and this is connected to the aggregation level of the practice.

*Nine types of attentiveness*

Our data show that attentiveness occurs in different forms. For example, the attention to the pain of a patient differs from being attentive to the patient who is in pain. The attention one needs to ensure that patients take their medication differs from the attention one uses when noting that those medicines are still on the bed table some hours later. Keeping an eye on a patient's use of medication in order to prevent adverse effects in the long term, requires another different kind of attention.

We know that attentiveness occurs in a multitude of forms and shapes which are all about attentiveness, even though they do not always look alike. In the analysis we deliberately kept the concept of attentiveness vague and open. It can be anything, and it may take many directions. Wittgenstein (1953 in Stern 2004) explains that concepts sometimes have family resemblance without them being alike. He argues that things which may be thought to be connected by one essential common feature may in fact be connected by a series of overlapping similarities, where no feature is common to all. Certain sub-acts come in line (i.e. the eyes of the aunt), but you cannot definitely say what the characteristics of the family are. The various types of attentiveness seem to be related in a similar way. It is not that the different types have the same characteristics on constant variables, however they belong to the same family (of attentiveness). The different types of attention are each associated with a slightly different view of attentiveness; sometimes it is something social, sometimes it is about concentration, and so on.

The forms of attentiveness that emerged in this study differ in the duration and course of the attention (continuing or broken periods), the focus of attention (what is the object), the

flexibility of the attention (degree of susceptibility to interference), the transparency of the attention (it is clear how the focus is and why), and the social and moral value of the consideration (how it is experienced by the receiver).

In our analysis of 22 cases, nine types of attentiveness could be derived from the patterns that emerged in the process of constant comparison. In all of these types, we find a typical composition of patterns; they all have a certain goal and a strategy to achieve this goal (see Table 1).

The distinct types of attentiveness help to understand its dynamics in health care practice. However, these types are not static. Attentiveness may change types gradually, for example by starting as very professional and disease-oriented and evolving to a more relationship-oriented type. The types overlap, are not mutually exclusive, they change constantly, sometimes they are phased and they are instable, there are characteristic co-occurrences, and so on. It should be noted that the types cannot be seen as too static and this must be taken into account when explaining the types.

Table 1. Types of attentiveness with goal, strategy, short description, and illustrative data fragment

| **Attention type** | **Leading mechanism / goal** | **Central strategy** | **Short description** | **Data fragment** |
|---|---|---|---|---|
| Relationship-based | Relationship | Tuning to the patient | This attentiveness is relational and its central strategy is tuning to the patient. Characteristics are using knowledge about the patient, keeping a broad view, togetherness, sharing, space to change goal or plan, sensing, daring to ignore or bypass contextual pressure, putting self on the line (using humor, emotions play a part, etc.), care as a practice. | "They are young men of the same age. They both have this careless manner and they make each other laugh; they like to dare one another, they are well matched." "The patient has not only been assisted by the nurse in a good and relaxed way, he has also been seen as a nice young man by someone his own age." |
| Meticulous | Completeness | Controlling | Meticulous attentiveness is focused on completeness and the central strategy is control. Meticulous attentiveness responds to whatever arises. Step by step, a response is given to each aspect. The good thing of this attention often mainly consists of the value of a certain gesture: taking time, explaining everything once more, mentioning all aspects, taking someone or something seriously, etc. | "At first, she defends the hospital's methods. Then she continues to ask questions about what is going on and addresses the content of the answers (defending the way things go: that's the way things go here. and: miscommunication.) and then she addresses madam's behaviour (taking away hope, addressing madam about her anger)." |
| Calculating | Coping with patient's resistance | Persuading | Calculating attentiveness is characterized by having to deal with a patient who wants something else than the caregiver. Persuading is the central strategy. This includes having a clear goal, communicating well, creating | "The oncologist has already made a plan for treatment and he wants madam to consent. But she doesn't do this right away. [...] The oncologist opts for taking a detour: he puts into words what madam wishes and he bases his policy on |

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| | | | confidence and confirming patient in his opinion. Persuading is driven by good intentions, but it is one-sided. Although the caregiver thinks he is acting in the interest of the patient, as long as he does not check this, it is only a lucky shot if it turns out well. | them. He could have disobliged her, but he chooses to change direction and take a positive route." |
| Tolerating | Maintaining position as a doctor, maintaining relationship | To accept, endure | This attentiveness condones. It must deal with the patient going beyond the pale in the vision of the caregiver. In these cases, a 'difficult patient' is not reliable, does not keep promises, and wants to be treated on his own terms only. The caregiver encounters his own repulsion, and chooses to endure it. Tolerating attention is characterized by keeping an eye on the patient as much as possible, communicating friendly, maintaining the relationship, relinquishing control, condoning, acting a role, and treating the patient on his own terms. | "For the oncologist, it is a surprise that Mrs A. is in the waiting room. 'She doesn't show up nine out of ten times', he says. He explains that this is a lady from Curaçao who never does what she says. This is quite difficult for him, because he can't figure her out. She's also long overdue for having her blood sample taken, but this is not happening either. 'She also kisses me each time', the oncologist timidly adds." |
| Settling | Keeping exchange-relationship proportional | Avenging | Settling attentiveness aims at balancing the crooked exchange-relationship by 'revenge'. The caregiver first had a broader view, but the focus reduces. Caregivers reason from a consequentialist rather than a deontological discourse. Something that first was good in itself, is now only good if the result will be good. This occurs e.g. when a patient has crossed the caregiver's boundaries and therefore no longer 'deserves' good attention. | "Another nurse is going to prepare the home medication for Mrs. E. 'I do it for two days', she says, 'exactly as promised. And I will not add anything she can get a hold of herself. Paracetamol is also on the list, but I will certainly not get her that, since we all have to pay for it ourselves.' The researcher notices the nurse blames Mrs. E. and is angry at her. No understanding or feelings of compassion are noticed (which the researcher experiences herself)." |
| Avoiding | Ease, uncomplicatedness | Evading | Avoiding attentiveness aims at ease and simplicity and to achieve this, the caregiver evades certain things. He wants to finish something and has no regard for what further arises. Avoiding attentiveness is characterized by a narrow view, being attentive to one single object, and a one-sided interpretative framework. Avoiding attention comes in different variants (ignoring/laughing off/ rejecting/passing onto someone else), but it is always characterized by one-way traffic. There is no sharing or transparency; the patient is not a partner in the deliberation, and the caregiver disregards that patient is connected to others (e.g. family members). | "For instance, they are having a bit of a laugh about the patient, really ignoring her depressed mood and not offering any opening for addressing it. [...] Madam has been ill for a long time, she will probably never get better and meanwhile she is ending up in hospital time after time. The caregiver in this case knows her well enough and interprets her mood and behaviour in a static manner: he mentions that madam's gloominess is part of her character and also that her realisation that her physical condition is unlikely to improve and the problems will keep coming back doesn't boost her mood either." |
| Process-oriented | Correctness, efficiency | Streamlining | This mechanized, streamlined attentiveness aims at correctness and efficiency, and the central strategy is streamlining. The attentiveness is characterized by relationship-negligence (the relationship is not important; not as a goal nor as a directive mechanism), having no eye for the patient's perception, a narrow repertoire so that no alternative actions come into view, a paternalistic professional attitude and being uninhibited (having no | "Each time the patient asks about something she could have known, the caregiver focuses on her partner: The caregiver has a general knowledge about what brain tumour patients are like (slow, confused, forgetful). It is hard for her not to have a biased view. At first, she had a reasonably wide view, but this only one particular silly question from the patient causes her to switch to the stereotype image immediately. She addresses mister. This is a |

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| | | | reservations). The caregiver has a narrow focus and works concentrated. The goal remains unchanged. | confirmation of madam's 'deterioration'" |
| Hurried | Finishing tasks a.s.a.p. | Rushing through | This hurried attentiveness is task-oriented and aims at finishing the specific task as quickly as possible. It is characterized by haste, speed, course fixed imperturbability, one-way communication, tunnel vision (own frame of reference is most important), a paternalistic attitude (caregiver has different assumptions about what is good for the patient), ignoring the patient's experience, and often an attempt to compensate through friendly communication / empathy. | "The patient receives information from the physician; this is a case of *one-way traffic*. There is no space to pursue what the patient is experiencing. However, it is implied that there is though when the physician responds to her complaints by asking "How are things in general?" This is his way of trying to shift focus and to make sure madam will say/see something positive. In doing this, however, he passes over her concerns." |
| Disciplining | Discipline, order | Keeping everything as it should be in accordance with the procedures | Disciplining attention is characterized by caregivers who want to keep everything as it is, or as it should be in accordance with the procedures. The routine (in the department, of the day, and so on) should proceed and there is no room to deviate. The attention aims at maintaining order and is not inventive or creative; the patient must abide by and comply with the regime. Features: a paternalistic professional attitude, the caregiver's interpretation is most important, a compartmentalized view, presuppositions. Disciplining attention is different from hurried attention because it is not about a specific job to be done. It often occurs along with process-oriented attention. Disciplining attention also aims indirectly at a good production process, but focuses on the disturbing things. | "The patient wants something and he is stubborn about it. He keeps trying over and over again. To the caregivers, it is not quite clear what he wants. His behaviour doesn't fit the picture. The nurses aren't thinking out the box. They don't show any creativity whatsoever in finding other solutions. The patient is becoming more and more of a caricature; this causes for a further decline of their willingness to take him seriously. The fact that he is seeing a psychiatrist and is taking haldol justifies the nurses' view of him as 'crazy'." |

*Caregiver's definition of care crucial for attentiveness - the theory*

Why does a caregiver practice one type of attention and not another type? The first thing that appears to be of crucial importance, is whether attentiveness is essential for giving care in the opinion of the caregiver. The term 'view' can refer to a subjective opinion, a shared ideology of a profession or a cultural matter of course in the local culture. In this study, we could sometimes hear the views literally ("this is how it should be"), sometimes we can see them (for example, someone is corrected in a particular direction), and sometimes the idea is to be inferred (who is always doing like this, seems to think that...). Furthermore, views are situational and not necessarily fixed: in one and the same caregiver different views of good care may prevail in different situations.

The data show large differences between caregivers when it comes to the issue whether care can do without attentiveness or not. Caregivers have practices in which numerous tasks are

demanded and they struggle with the meaning of attention in there. Is attention essential for the performance of tasks, is it handy, or may it even be an impediment? Four positions are found.

1. The first position contains the view that being attentive is constitutive for giving care: in this view, the caregiver believes that if the care does not arise from being attentive, care ceases to be care. In this view, care achieves its goals, precision, alignment and ultimately its form and content by means of attentiveness. Attention is the condition of possibility for care, and it is clear what care thus is in this view and when it may be called 'good'.
2. A second position comes to the notion of 'attention as institutive', i.e. as a (welcome) contribution to the (good, effective) organisation of the many tasks a caregiver has to perform. Here, the view is that being attentive helps care further; it eases or organises care in an appropriate way, and matters for that reason. The underlying concept of care is somewhat different from the former but nevertheless related; the biggest difference is the meaning of attentiveness to care: a creative condition (no care without attention) or a useful tool for the proper design of the already existing care (which would be barren, cold and unilateral without attention - but still it would be care).
3. The third position is rooted in the belief that paying attention constitutes neither arranges but rather complicates the caregiving. This is partly because attention is considered as an extra task on top of those a caregiver already has to perform: attention makes it harder, heavier and more complex, and attention also leads away from the necessary tasks to be done. Here the underlying concept of care is distinctly different from the first two: it is particularly narrower. Attention is considered a nice touch here, and it makes things only *easier* if there is no space for it.
4. The fourth position we found is an enlargement of the third and the radical opposite of the first: being attentive impedes care and makes it impossible. Although in certain situations respectable and understandable, the definition of care is very strict and limited here, and being attentive and what this involves is considered an impediment: it hinders you in getting the work done and gets you into all kinds of hassle, which is the last thing you need as a caregiver. If there should be attention to the patient himself this is rather a task for someone else, e.g. a social worker, psychologist, or chaplain, or someone from outside the hospital.

It will be clear that this variable 'relationship care ↔ attention' relates to the question whether attention constitutes and gives shape to the fulfilment of care (position 1 and 2) or prevents care and makes it heavier or shapeless actually (position 3 and 4). On this axis, the continuum is thus

from making possible to making impossible. However, to answer the question why someone gives the attention he or she gives, a second dimension has yet to be developed.

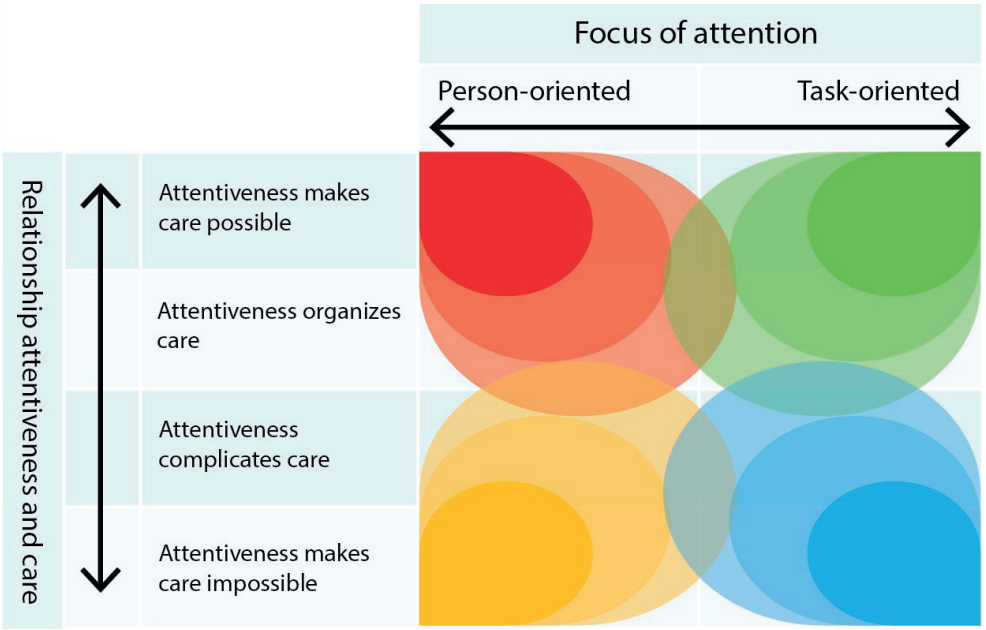
The second dimension is about the focus of attention: on what is the caregiver (mostly) focused? We look at attention directly here; this differs from the first dimension in which we looked at conceptions of caregiving and the role of attention therein, which therefore was an indirect way of looking at attention. The second variable is also simpler. However, perceptions play an important role here as well: what is the actual task of the doctor or nurse, which is the core business, and what am I as a professional first of all kept to? In this study the focus of attention can often be easily determined, though it is sometimes unclear, because besides immediately observable behaviour there is also postponed behaviour. Because of the latter, sometimes it appears with some delay that something was actually noticed ('in the attention').

Caregiving by doctors and nurses is always ambivalent; on the one hand it concerns the body, and on the other hand it also involves the person from whom that body is. From the perspective of the body, the attention is focused on the disease or condition, on the technique to gain insight in that, and on the operation to take away or alleviate the problem. Attention with this focus tends to his business-like; directed to the thing, the job, the procedure, the wound, the blood, etc. in which the person of the patient is pushed into the background. He or she appears only in such way it helps to do the right job or to do the job well or even as nuisance to do the necessary work efficiently. The attention is then for example focused on whether the patient is lying still, cooperating well or giving useful info. The person-centeredness is embedded here in the task-centeredness.

From the perspective of the patient as a person, the attention focuses on the person who has the disease or condition. Here the task-centeredness is embedded in the person-centeredness: what you do, and how, and to what extent depends more on the patient and what the caregiver through their relationship believes he needs, than on the disease itself. The two different focuses give the performance of the task a typical direction and substance, but they are not mutually exclusive: they can go together and follow up each other.

When combining the two dimensions a space is created in which the types of attentiveness can be situated (see Figure 1).

Figure 1.




Four extreme positions are found (the corners of the figure), among which many intermediate positions are possible. In reality, there is overlap between the four positions; the various forms of attention often have features from more than one angle. Top left of the figure we find the attention types that are rooted in the belief that being attentive is essential and determines the origin and structure of the care or task performance: the attention is focused here on the person the patient is, with his history, experience, knowledge of the disease, moral boundaries, desires, and so on. For example, we see a nurse who rubs a woman's painful mastectomy scar with some oil. The nurse has a clear awareness of the potential pain or emotions of the patient. There is both attention from someone who knows about scars and from a woman who knows how it is to expose oneself as an amputee, or to be ashamed.

Top right of the figure we find the types of attention rooted in the belief that being attentive is essential and determines the origin and structure of the task performance: however, the attention is focused here on the disease and the care task itself. For example, we see a doctor who meticulously does a bone marrow biopsy. By carefully following the steps of the protocol and not to be distracted, he can perform this delicate intervention well.

Bottom left of the figure are the attention types rooted in the belief that being attentive too easily and with unwanted consequences diverts and aggravates or makes caregiving impossible: only if the attention is restricted ("I do not look at the person now"), what needs to be done can be done. One attempts to keep the person-focused attention short and tight. The idea is that the best person-focused attention helps in keeping the job not too heavy. It is not necessarily thought that one should go away from the person and focus on the task: instead, by focusing on the person on one specific, tight and measured way, a mitigation of the task occurs and the work will get on well. An example is a doctor who wants to convince a patient to undergo a certain treatment. By focusing his attention on a certain way to the patient and his history and desires, he manages to persuade the patient.

In the bottom right corner of the figure we find the attention types that are based on the belief that attentiveness too easily and with unwanted consequences diverts and aggravates or makes caregiving impossible: as in the previous position it is believed that only if the attention is restricted, what needs to be done can be done. Here, one attempts to keep the *task*-oriented attention short and tight. The idea is that the best task-oriented attention helps in keeping the job workable. Only when all attention paid to the person is blocked or restrained, the focus can be on the task itself. An example comes from the way in which the nurses treat a confused patient during a night duty. The patient is wandering around, talking incoherently, and using antipsychotics. He is not taken seriously. Instead the nurses try to calm him and restrain him in leaving his room. The attentiveness becomes disciplinary in nature: the patient must adapt and participate in the normal routine of the ward. The attentiveness is not focused on the things that bother the patient. The needs of the patient are avoided because the attentiveness is aimed at ease and simplicity.

*Three cultures of care: socio-institutional enclosure*

Certain types of attention end up in the same corner of the figure. Along with some differentiations, they have much in common in many areas. We have shown above that if caregivers have *those* beliefs and meanings, they will (probably) give the attention of *that* kind. The question of this section is: why does a caregiver actually have those beliefs and experience those meanings? Why are these up to date and no other, or why are other less powerful?

The empirical findings suggest that two things are decisive. In order to understand their power and effect one must realize that a modern hospital is initially focused on healing and relieving pain, and therefore focused on the biological, physical side of the patient. This orientation on the physical body is embedded in dozens of things: the design of the building, the

socialisation of caregivers, the caregivers' view of their own profession, the ways in which one is assessed or controlled, the expectations of patients, the public benchmarks in which hospitals are compared to other hospitals, and so on. We call this the socio-institutional enclosure of the caregiver. It is interesting that although the socio-institutional enclosure is more or less the same everywhere, caregivers differ in the extent to which they come loose from this pressure. We find a difference between conformists and people that are more autonomous. It is essential whether a caregiver is receptive to group pressure, whether he can be contextually independent, whether he intensively gets along with colleagues, feels to be breathed down his neck or not, and so on.

Many of such examples passed in review in this study, but as they are not explored in detail, it is not possible to do any definite statements. Nevertheless, we can certainly distinguish the caregivers who are tightly enclosed socio-institutionally from those who feel only situated or facilitated socio-institutionally. The first experience little room to deviate from the formal core business, whereas the second are able to move around the core business and are focused on more than only the body. The degree of enclosure has an objective side (inspections, the building, rules and agreements, etc.) but also an subjective side (what you experience as elbow-room or rather as a firm duty or task).

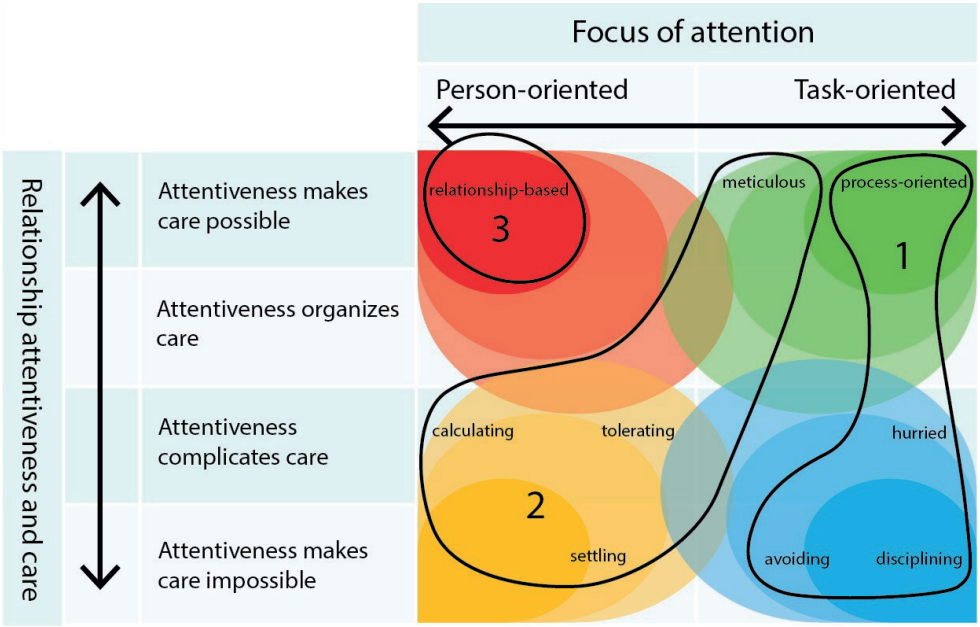
On the subjective side this socio-institutional enclosure is strongly influenced by the caregiver's conception of care. It is crucial whether the caregiver's definition of care is inclusive or exclusive i.e. including the person that the patient is or not. We call an exclusive definition of care self-referential: in this case, the care is focused on the physical body and everything revolves around that (that is the point, that is what the language and conceptuality are derived from, and from that comes the logic of work). Anything that comes up is included in this self-referential conception of care, thereby stripped of its strangeness, and unified. In contrast, we find an open, permeable definition of care in which the influence (voice, knowledge, desires, morality, etc.) of the patient is included. We have called this conception of care relationship-centred. We have seen caregivers who, regardless of the objective power of the socio-institutional enclosure, have an open conception of care that is focused on the relationship. This may get stuck tremendously, but in certain situations it functions as a counter force, a strong desire, or an ideal, and that way counterbalances the socio-institutional enclosure. In that case, the subjective dimension of the socio-institutional enclosure is nourished by a relational conception of care and thereby provides a counterbalance: a sense of space is created which can be filled by working relationally as best as possible. Another picture is brought into vision when the subjective side of the socio-institutional enclosure is filled with a self-referential conception of care: in that case a further

concentration is seen on body-oriented, fixed, uncompromising duty performance of the caregiver.

This mechanism significantly explains why there are affinities or differences between the different types of attention. At the intersections of more or less strong (really existing or experienced) socio-institutional enclosure and self-absorbed body-oriented or relationally open conceptions of care, we find cultures of care in which the attention types fall and which explain the types to a certain extent. We distinguish (see Figure 2):

1. Self-absorbed culture of care: high socio-institutional enclosure, dominance of the importance of the objective dimension, self-referential conception of care.
2. Open culture of care: high socio-institutional enclosure, some space in the subjective dimension, conception of care in which the importance of recognizing the person of the patient
3. Relational culture of care: the socio-institutional enclosure is there and provides the context is which the care is situated but the caregiver also experiences some room, is sometimes contextually independent and strengthens that position by a cultivated and experienced conception of care that is open to the care receiver.

Figure 2.



## Discussion

Attentiveness has often been reported as an important factor in health care but there is a lack of adequate and rich concepts and theories for thinking about and supporting it. In this qualitative study we turned to actual care practices in a hospital and examined how attentiveness appears. The analysis of the data showed that attentiveness occurs in different types, which are characterized by a certain goal and a strategy to achieve that goal. Some of these types may contribute to good care and should be encouraged. However, attentiveness may be deployed for a specific purpose. It is normatively charged and its outcome for the recipient may not always be good. Attentiveness derives its value from the underlying goal. What attentiveness is focused on determines whether it is well-doing. For example, something may be a clever surgery, but does not necessarily have to be good care. These findings differ from other studies, in which attentiveness is understood as something good by definition (e.g. Barnes 2012; Baker-Ohler & Holba 2009). It furthermore shows that attentiveness should not be equated with communication; a caregiver may be very friendly and communicating well without being attentive to what is at stake for the patient. This highlights the importance of studying attentiveness as a separate phenomenon when it comes to the quality of care as experienced by patients. Furthermore, since attentiveness proves to have many facets, it is recommended that further studying attentiveness starts with discerning the different "angles" of attentiveness, such as concentration, interest, alertness, and so on.

The data collection of this study was limited to an oncology department that is located in a general hospital in the Netherlands. Oncology is a specific department, at which caregivers generally seem to be more attentive to patients' experiences than e.g. at orthopedic departments. We suggest that certain patterns are tenable to other departments and other countries, but that some other mechanisms would change. This, however, are issues for future research.

This study shows that socio-institutional enclosure is an influential factor in the occurrence of attentiveness. Many explicit or implicit signs of patients do not linger in the perception of caregivers but are swallowed up in other, stronger attention grabbers. This raises the question of the influence of patients themselves. A limitation of this study is that it did not examine the role of the patient. What is the role of the patient as a constituent of attentiveness? The patient, i.e. his person or character, is a dynamic variable in the development of the type of attention. Whether patients should be assertive to get more attention, and whether this should be their responsibility, would be interesting questions for future research.

Being attentive depends in part on the individual caregiver but the conditions, understood as socio-institutionality, play a decisive role. Findings from this study emphasize that one should not focus on individual caregivers in order to improve attention, but also look at organisation-wide processes. Attentiveness has a political and institutional dimension. It is interwoven with other major processes and there is much pressure on it. Caregivers may have a pretty good opinion or vision, but as soon as they for example join a team, or perform an intervention with three colleagues watching, their vision evaporates. Whether the view of a caregiver persists, strongly depends on whether it is given room. However, the findings of this study particularly uncover examples of caregivers being stuck up in the institution.

Douglas' grid-group theory (1975, 1982) is often referred to in order to understand to what extent people are constrained in terms of group membership and patterns of social relations. The theory conceptualises four main types of social organisation co-existing in different degrees of dominance in every society; they are in conflict with each other in a constant dynamic. The four types are plotted on a graph with two axes, and these provide an understanding of how socio-institutional enclosure works on different levels. The horizontal axis represents the strength of group norms, such as family and local community, the extent to which an individual is incorporated into bounded limits, while the vertical axis represents the experienced strength of the grid - those less intimate mechanisms of control such as laws, religious authority, economic forces and institutional disciplines. Grid refers to the degree to which an individual's life is circumscribed by externally imposed prescriptions, the less of life that is open to individual negotiation. Caregivers do not only experience socio-institutional enclosure amongst colleagues in the hospital, but they are also part of the larger society which becomes manifest in how care is organised and regulated with all the major and minor implications involved. These different levels of social organisation are closely interwoven, and together these patterns of constraint will match the ways that caregivers construe their ideas on professional care. Care is delivered by a range of individuals and teams from different professions which have their own distinct cultures, identities, educational backgrounds, objectives, rewards and incentives (Morgan & Ogbonna 2008) and which all share a strong awareness of those cultures, of relative status differences and of the boundaries within and between the different professions. Not only are caregivers aware of these differences and boundaries, but a key part of everyday working life for professional caregivers is establishing, maintaining and defending them (Nancarrow & Borthwick 2005). The findings of this study confirm that professional identities and cultures thus have a significant impact on how individuals work, with implications for the care that patients receive. A lot of behaviour is (implicitly) already established for caregivers.

This study was focused on attentiveness as a crucial component of good care and suggests that socio-institutional enclosure does not always promote attentiveness. Caregivers who have a substantive view on care that includes the person of the patient and who experience room enough to cultivate this, are the most attentive to patients. Resultingly, socio-institutional enclosure comes to the fore as hindrance for something good, and is therefore quickly regarded as something bad. Understanding socio-institutional enclosure mainly as impediment, is a limitation of this study. Socio-institutional enclosure should not only be understood like that. Apparently, it is also something that is needed for care, something in which care thrives well. As mentioned before, caregivers are continuously supporting the culture of enclosure and developing it further through processes of socialisation. They reproduce those structures by their acting, and that reproduction is at the same time a change and reinventing of the structure. This is in accordance with the so-called structuration theory of Anthony Giddens (1984). Therefore, future research should be concerned with understanding the socio-institutional enclosure. Why does care need it? What is the importance for caregivers? Do the implications of socio-institutional enclosure make them a better caregiver? Is it essential for the organisation of the care work? When the need for socio-institutional enclosure would be understood, it may be explored how attentiveness can get a more prominent place in health care considerations.

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Methodological intermezzo:

# CONSTRUCTING GROUNDED THEORY

As this thesis leaves little room for the presentation of complete case descriptions, this interlude is meant to present one case as a whole and to show how it, through the process of analysis, ended up and informed the grounded theory.

**Case example from the raw material: Mrs. E**

Mrs. E (44) has visited the hospital regularly the last months due to cervical cancer. She also has heart problems and is treated by a cardiologist. At this moment, she is admitted to the nursing ward. Mrs. E. is a thick, working-class woman that is very friendly. The researcher has met her several times before, but this description is about the last time on the ward, which left the researcher with a bitter taste. The appeal experienced by the researcher is shared by a number of nurses, but for various reasons this does not move them to action.

Nurse Anne comes to the medication room and tells nurse Suzan and me that Mrs. E. does not want to leave the ward to go home. "She has two faces that woman, I never noticed!" she whispers to us. Mrs. E. does not want to go home because she has got no home. She has postponed her discharge as long as possible, but now the oncologist sees no more possibilities to extend her stay any longer. It seems that Mrs. E. is (or was) married to a Turkish man, but they broke up. Mrs. E. has told the head nurse that if she calls her ex-husband to pick her up from the hospital, he will beat her up. She does not know where to go. She does not dare to go to her mother, as she does not want her to find out that she has no house (anymore), and that she has no money and many debts. Apparently, in conversations with the oncologist Mrs. E. has never been clear about these problems. He did know about the difficult home situation, and he offered her help from e.g. social work, but Mrs. E. refused. The caregivers have noticed before that Mrs. E. has two children who never visit her; she has said she lost contact. The nurses find it difficult to force Mrs. E. to leave the hospital, but they do not know alternatives. The researcher also senses clearly that according to the nurses it is Mrs. E.'s own fault: as she refuses any support, how are they supposed to help her?

One of the nurses is going to prepare the home medication for Mrs. E. "I do it for two days", she says, "exactly as promised. And I will not add anything she can obtain herself.

Paracetamol is also on the list, but I will certainly not get her that, since we all have to pay for it ourselves." A little later nurse Anne comes to tell that the head nurse has suggested that "one of us should go downstairs to see whether Mrs. E. is picked up". Nurse Suzan, who is Anne's supervisor, responds that Anne should not do that. "What do you want to achieve? Will we take her back if she is still there? No! We can do nothing for her. If you go downstairs this may seem very promising, but it makes no sense. Besides, it is at the expense of the other patients at the ward." Anne nods. The researcher notices the nurses blame Mrs. E. and are angry at her. No understanding or feelings of compassion are noticed (which the researcher experiences herself).

**Case description according to the standardized exploratory model**

The first step of the analysis involved initial coding. Interpretative case descriptions of the data were written. Then, the analysis switched to focused coding. In order to enable a comparative analysis, the interpretative case descriptions were examined for their common elements. After that, the analysis involved theoretical processes of coding. The common elements, or description categories, were summarized in a descriptive standard model of attentiveness. This model makes it possible to describe being attentive adequately on the basis of inductive and free descriptions, through which the different cases of being attentive become mutually comparable.

*Perception*

The picture that emerges from reading Mrs. E.'s case is that Mrs. E. is a patient who irritates: the woman is stubborn, uncooperative, she smokes, and so on. Furthermore, she represents a "cultural clash": her appearance and behavior are different from those of the doctors and nurses. Mrs. E. complicates matters further: medically there is much wrong with her, she conceals things, etc. In organizational terms Mrs. E. is difficult to handle. Her characteristics are at odds with the preferred patient images and the current medical or nursing discourse. Therefore she easily burdens caregivers with a difficult task.

*Experienced space for attentiveness*

The caregivers discover their personal limits. The nurses are disappointed and angry because Mrs. E. did not want to be helped and they blame her for holding things back from them. As the nurses feel wronged they try to obtain satisfaction: one of them gives the patient as few home medicines as possible out of some sort of revenge. Whereas the nurses first looked broadly, they now narrow the attention because they have the experience of becoming exhausted when the

exchange aspect of the relationship is disproportionate. Furthermore, nurse Suzan finds it pointless to go downstairs to have a look at Mrs. E. because they will not take her back on the ward if she was not picked up. Nurse Suzan assumes that Mrs. E. can only be helped through re-admitting her, thereby overlooking that "having a look" may be a meaningful act itself and be of support. Finally, it is important to note that the turbulence of today on the ward and nurse Suzan coming up with the argument of aggrieving the other patients on the ward, may also be seen as contextual factors of influence.

*Process of object finding*

When looking at the process of object finding in the case of Mrs. E., we see caregivers responding to the behavior of a patient which they become aware of through the reporting of a fellow nurse. They act on basis of a particular image of her (or perhaps because their previous images of her are shaking) that moves them emotionally leading to a rigorous decision. They do not ask themselves how they can support this patient however possible, but
restrict as they find she does not deserve it.

**Towards a type of attentiveness**

This case example reveals a narrowing attentiveness. At the beginning, the attentiveness was broad but it has shrunk to purely functional. The nature of the caregiver-patient relationship can be characterized as "efficient" and as such the quality of the relationship is moderate: the most necessary things such as the preparation of medicines are done for the patient. However, from the care ethical viewpoint on good care, this attentiveness and relationship seem to fall short: the situation asks above all not to leave the patient but eventually the patient has been abandoned.

*Type of attentiveness*

The attentiveness in this case example was identified as 'settling attentiveness'. It aims at balancing the crooked exchange-relationship by 'revenge'. The caregiver first had a broader view, but the focus reduces. Caregivers reason from a consequentialist rather than a deontological discourse. Something that first was good in itself, is now only good if the result will be good. This occurs e.g. when a patient has crossed the caregiver's boundaries and therefore no longer 'deserves' good attention.

**Looking back on this case from a grounded theory of attentiveness**

When looking at the grounded theory of attentiveness that emerged, we see that this type of attentiveness type has end up in the bottom left corner of the figure (see figure 1 in chapter 7). Bottom left of the figure are the attention types rooted in the belief that being attentive too easily and with unwanted consequences diverts and aggravates or makes caregiving impossible: only if the attention is restricted ("I do not look at the person now"), what needs to be done can be done. One attempts to keep the person-focused attention short and tight. The idea is that the best person-focused attention helps in keeping the job not too heavy. It is not necessarily thought that one should go away from the person and focus on the task: instead, by focusing on the person on one specific, tight and measured way, a mitigation of the task occurs and the work will get on well.

7

# How can attending physicians be more attentive?

## On being attentive versus producing attentiveness

Klaver, K. & Baart, A. *Medicine, Healthcare and Philosophy;* forthcoming

**Abstract**

This article is about caregivers being attentive to patients in healthcare. From earlier work on the understanding of the other, we know that it is impossible to completely understand the experiences of others. By the sharing of subjectivity - intersubjectivity - we may try to 'grasp' the other's point of view. However, we can never assume that the *same* experience produces the same *experience*. Now, if it is principally impossible to understand the experience of one another, and if paying attention always implies an understanding of what to pay attention to, then how is it possible to be attentive to the experiences of those who are entirely at the mercy of our care? How can caregivers perceive the impossibility of understanding the experiences of patients as an appeal to be attentive to their experiences? This is discussed in this article. It departs from the authors being confronted with inexplicabilities in the empirical study of attentiveness in healthcare. It presents two examples and discusses the meaning of these emergent properties. This leads to a discussion of the existent literature on the indefiniteness and openness of attentiveness. It becomes clear why, although we can understand and predict much of it, attentiveness will always be characterized by a certain uncontrollability as well.

7

# How can attending physicians be more attentive?

## On being attentive versus producing attentiveness

### Introduction

Paying attention is a process of directed observation of the environment. It has different characteristics, but it always involves observation, or perception, and interpretation. If you are paying attention to something, you take something *as something*. For example, you see something circular as a ball. Or as a balloon. Or as the belly of your pregnant friend. What you perceive is not fixed, but it is meaningful and thus an interpretation of what occurs. Your attention to the balloon is associated with understanding that what you see is a balloon. What you feel does also play a role in attentiveness. Your attention to your pregnant friend's belly, for instance, is associated with your joy about the fact that she is expecting a child.

This also applies to care. For example, your attention may be drawn to a patient who is crying. However, you do not know what that crying means. Maybe you can find it out by asking, but that is not always possible, due to the circumstances or because the patient does not tell you what the matter is. Then what? In practice, this often means that the caregiver's attentiveness moves away and focuses on something he can do something about or something he can understand instead.

We, caregivers, have to understand patients. Interest in the patient's experience is growing in all facets of health care, which is shown by the increasing number of health care institutions making 'patient experience' a strategic goal, insurance companies that want to gain insight in the quality of the patient experience to rely their policy on, the increasing amount of 'lifeworld studies', and so on. In the healthcare sector, mainly dominated by the medical profession, it becomes more and more clear that we not only need to understand about diseases, but also about the people who suffer them. The notion of 'patient-centeredness' has increasingly influenced healthcare in the Netherlands and elsewhere. Patient experience has been given high priority. In the midst of consumer driven concerns, the aim has been to give patients more 'voice and choice' in their own health care.

Patient experiences have not always been a central value in the health care practice, since caregivers must pursue other values, such as strictly working according to protocols, finishing tasks in time, meeting production standards, or showing in a good light amongst colleagues. The experiences of patients are often moved to the background. Therefore, every patient's story, every study or other attempt to come closer to the experience of a sick person, is a major victory. However, since there are as many stories as there are people, the experience of one patient never speaks for another one. Patient experiences have to do something impossible, but something that is impossible to ignore as well: they must speak on behalf of others whose experience we do not know.

In fact, generally speaking, it is impossible to understand the experience of a patient. When trying to 'grasp' the patient's point of view, sharing experiences with them seems the most appropriate approach. The sharing of subjectivity – intersubjectivity – creates moments of recognition and the intuition that we have 'grasped' the other's point of view. At the same time, however, we can never assume that undergoing the same produces the same experience. This refers to the problem of identification (Gadamer in Fay, 1996: 8-50). Gadamer would say it is essential for the understanding of an experience that the observer must be able to identify with the experience. He needs to understand it as a particular experience and assess it like that. The observer should be able to identify the experience; this identification makes it an experience. Another essential aspect of understanding an experience is that the identity of that experience can be understood only if the observer 'plays along'. According to Gadamer, the real understanding of an experience can only be achieved if there is an active attitude that establishes a meaning. This makes the observer a fellow actor in the experience. An experience supposedly consists of two aspects: the experience itself and the observer who plays along in the game of the experience. This makes it intrinsically impossible to understand the experience of the other in the same way as the other does.

Now, if it is principally impossible to understand the experience of one another, and if paying attention always implies fully understanding, then how is it possible to be attentive to the experiences of those who are entirely at the mercy of our care? How can caregivers perceive the impossibility of understanding the experiences of patients as an appeal to be attentive to their experiences? This is discussed in this article.

*Two propositions*

As this paper is about care and attentiveness, it must be clear what our view of care involves. In this view of care, attentiveness is a core issue. Our approach includes two main assumptions. These assumptions are common in care ethics, the theoretical approach in which our thinking is placed. The first premise is that care takes place in relationships. Persons, communities, and organizations are conceptualized as relational and interdependent (Held, 2006; Van Heijst, 2011).

The second premise is that care is always context-bound and situation-specific (Tronto, 1993). One can discern three forms of context: the physical context such as the place where you live, the social context that assumes that everyone is in a relational network, and the historical context that takes into account someone's biography (Klaver, Elst, Baart, 2014).

**Background of the problem: inexplicabilities in the study of attentiveness in health care**

Because attention is an essential element in good care and at the same time lacks a single definition, we conducted a qualitative empirical research. This study yielded a grounded model that describes different types of attentiveness and explains their occurrence. This model has been presented in earlier papers. In those papers, we have also stated that at the same time attentiveness always seems to escape the analysis partly. These inexplicabilities coming forward in the analysis, is the reason for this paper. Although we can identify what factors are of influence, there is still something in the emergence and the nimbleness of attentiveness which we cannot grasp. In the analysis we have described different types of attentiveness and we have seen how these emerged. We have looked at complete cases, i.e. from the emergence of attentiveness to its outcome for the patient.

This means that the effect of the attentiveness is included in the nomination and description of an attention type. We have described the various factors that have affected the outcome. Yet this is not a process of cause and effect which can be applied reversely as well. Even if the influencing factors are the same, another type of attentiveness with another result may emerge. The explanation of attentiveness is deficient.

For example, the circumstances may be structured in such a way that based on what we have learnt about attentiveness, the attention is expected to be very brief and focused. Nevertheless, the caregiver may suddenly perform attentiveness of an open kind. Apparently, the caregiver did experience the need and space to be attentive in an open way, while this was not the case in similar situations. From the analysis, it became clear that the occurrence of attentiveness is

always associated with something unpredictable. In the literature, this is described as the result of emergence. Emergent properties (Johnson, 2006; Sawyer, 2003; Rehder, 2003) can be thought of as unexpected, unaccountable, and untraceable behaviours that stem from interaction between the components of attentiveness and their environment. Although attentiveness can be understood to a large extent, there is always a moment that escapes the prediction. Many factors can be explained but at the same time attentiveness will always be characterised by a certain uncontrollable aspect. Attentiveness has to do with a layered causality and this implies that a certain irreducability and unpredictability is to be included in the analysis.

**Emergence on the level of the caregiver**

Emergent properties are explained above as unavoidable elements in the complex practices of attentiveness. In this section, we will extend this idea and propose that this inexplicable nature is not only an unavoidable element but also an indispensable ingredient of good attentiveness - and therefore, there should be space for it in healthcare.

As we have shown, when analysing the data, we as researchers knew what the effect of the attentiveness had been, and therefore we gave a certain type of attentiveness a certain name. Thus, the effect of attentiveness is included in the understanding of the type occurred. However, the caregiver does *not* know in advance which type of attentiveness is going to appear[13].

In the cases of the more 'open' types of attentiveness, when the attentiveness is not (yet) or not exclusively focused on one object, the caregivers often make a guess and they do something which is not directly deducible to a concrete goal, or they refer to something they cannot quite predict or control. This is what we call emergence on the level of the caregiver. We will illustrate this by means of examples. We present two case descriptions from our study, and then explain that emergent properties seem to be at work.

The first example is about a physician-assistant who has a very stressful day. As his colleague is ill, he must visit patients on other wards and also help out in the emergency department. In the afternoon, he does his round on his own ward. A visit to this patient was not planned, but a nurse asks the doctor to. The patient is a man with cancer in an advanced stage who has trouble eating. He is sitting on his bed in T-shirt and underpants. There are flowers on his bedside table and children's drawings on the wall. The man has a frolic, round face and a big belly. He is worried about not eating well. "I used to be a gourmand, as they call it. But there is

[13] However, sometimes it seems to be like that: e.g. when a caregiver aims to 'give some attention'. But this is not what we mean. We do not necessarily understand the meaning of attentiveness in the same way as caregivers do.

little gourmand left", the patient says. The doctor replies: "Do you mean you are throwing up all the time, or that nothing tastes good to you anymore?" What follows is a discussion about optimizing the situation under all circumstances. It covers the patient's perception of the situation. The doctor is aware of the medical problems that have to do with eating, but he also has an eye for the wider, existential experience of the patient. By listening to the utterance of the patient, to the words he chooses, and by not only asking for the things relevant to the medical treatment, he leaves room for the perspective of the patient's experience to open up. Eventually, the case turns out not to be about having problems with eating food, but about being less able to enjoy life. This is an emergent theme.

Another example is about a lady who has recovered from cancer and now visits the oncologist twice a year for a check-up. She is a rather opinionated woman who takes little note of the advice of the doctor. She also laughs at her husband who is trying to influence her health behaviour through the oncologist. What we see is that the woman is playing with the doctor. She lies and cheats, and does not listen to him. In a sense, the patient exerts force on the doctor. However, the doctor continues to receive and see her. He plays along with her and listens to her little lies. Eventually, it all turns out to be about faith and loyalty.

The attentiveness that has occurred in the above cases, is of two different types. In the first case, the attentiveness is relational, which means that there is no preset goal, but what is at stake for the patient emerges in the conversation and the doctor responds accordingly. This is remarkable because the doctor is very busy and actually had other plans. The question he asks is in line with his stressful day: not quite open; however, it works out well. Our data show that in similar cases, there usually occurs at most a very focused, framed attention. In the second case, the attentiveness 'condones'. The doctor allows the patient to play with him a little. In retrospect, it appears that space has arisen for what is currently the most important for the patient, namely that she does the most necessary in order to stay healthy, and that she visits the oncologist for her semi-annual checkups.

In both cases, a different kind of attentiveness rises than we would expect based on the grounded theory (Klaver & Baart, 2015). As described earlier, the emergence of a certain type of attention is more than the sum of its parts. There will always be unpredictable parts, both for the caregiver and the researcher. These emergent properties originate from the interaction of the caregiver and the patient. In the relationship between them, things can come into existence that cannot be reduced to just either of them (Klaver & Baart, 2011). Secondly, the environment affects what may emerge as well (ibid.). In this study, the field (locus) of the emergence is the

caregiver. Properties that could not be predicted may arise from their interaction with the patient and the contextual factors.

Based on the data, we can distinguish between emergence on the level of perception and emergence on the level of social interactions.[14] The first stems from the operation of consciousness, perceptions, intentionality, reviews, moral sensitivity, etc. while the second is associated with work culture, the functioning of the team, the patient's assertiveness, the structure of the business aspects of the care, the course of the day (visits on the ward, outpatient, who was before you, etc.), and so on. All these forces come together in the caregiver, and although we can quite predict which attentiveness will occur from that, it fundamentally escapes our understanding which seems to be based on 'producing' attentiveness.

The idea of an existence of inexplicabilities is consistent with the care ethical assumptions that good care is always relational, context-bound, and therefore unique. From the interaction among people and between them and the environment, things may become visible that previously were not. This requires some openness in the attentiveness of the caregiver. By having open attention, i.e. attention that is not completely framed but receptive to what may emerge, a relationship may be created that is wider than just functional, allowing what really matters to pop up.

In current discussions on healthcare that must be attentive to patients, the emphasis is on understanding patients by obtaining as much insight into their experiences as possible (Department of Health report 2010). Consequently, more and more studies focus on patient experience and lifeworlds. However, the working of emergent properties shows that this is not enough. On the one hand, caregivers gain understanding by information on patient experiences. These can make them more sensitive to the various experiences of the patients they encounter. On the other hand, we also have to realize that health care professionals should not want to understand everything. Understanding also means defining or settling, and this is too static a meaning to be attentive to patients. Attentiveness should not only consist of your own active inquiry, but also by 'receptiveness' or the mode of 'letting things happen'.

The emergent properties make clear that good care also depends on the recognition of the indefinite. We see that attentiveness is often focused on an object, but for good care it is essential that attentiveness is open to a certain degree. Therefore, openness, or indeterminacy, should have a place in our thinking about care. Perhaps we must abandon the idea that attentiveness must always be focused on something. But how can someone be attentive without knowing what to focus on?

[14] The existing literature on emergence makes a distinction between strong and weak emergence (Chalmers, 2001; Bedau, 1997).

**Attentiveness: the indefinite as essential**

This paper shows that the occurrence of attentiveness is associated with emergent properties. This means that in the care relationship, due to the attention, something may come into existence that is often absent or invisible beforehand. We have illustrated this with some examples. It becomes clear that being an attentive caregiver is not always about trying to determine the object of attention, i.e. attribute a fixed meaning, but rather to postpone the interpretation, or to continue interpreting. Interpreting is understood here as a process, something that is not static, but moving. Gadamer (1997) describes an ever expanding circle of understanding and interpretation in which we approach a topic with some preconceptions, or projections. These projections are then examined and revised in the face of what "the things themselves" reveal to us. Then we return to a further exploration in the light of this new understanding. In addition, the topic is understood by viewing "the whole in terms of the detail and the detail in terms of the whole" (p.291). This dynamic movement of understanding from projection to topic to new projection, and from whole to part to whole, constitutes the hermeneutic circle of understanding and interpretation. Open attention should not only be described as actively searching. It is also a kind of waiting; a process of learning; a process of letting something come to you. This section discusses some authors commenting on this indefiniteness or openness.

Iris Murdoch, philosopher and novelist, shows in her essays from the 50s and 60s how morality is a matter of open attentiveness. For Murdoch 'looking', as an 'action of attentiveness', is a metaphor for 'seeing': forming a picture of the other as he really is. She illustrates this by means of a story about a mother who is not happy with her daughter-in-law, as she thinks her unpolished behaviour is not good enough for her son. However, out of courtesy, she does not show it. Consequently, because the mother does not turn away from the daughter, she does not stick with the rejection. As she continues to look at the daughter-in-law and tries to see through her unpolished behaviour, she focuses her gaze on just that part which is so difficult to see, and thus she 'looks for the best in her'. She tries to see the daughter-in-law not 'accurate' in the sense of logically correct, but she tries to see her 'right, to do her justice. The mother is not trying to understand what she sees; she only needs to see it 'clear'. According to Murdoch, this seeing clearly unfolds in a process of looking: in a process of "careful and just attention" (1997: 313). In this process, she is going to see other things: other conduct than the unpolished behaviour. It is a kind of looking that starts from the good in the daughter-in-law. As the mother is guided by the good, even though she only sees unpolished behaviour on the surface, she does the daughter-in-law justice.

Murdoch makes a distinction between seeing and understanding, or "seeing clearly" vs. being logical and correct. This difference is also cited by Andries Baart (2004: 55) when he writes about the Greek word "diagnoses". In this kind of compound words, "dia" usually means something like "going through something." "Gnos" can be translated as to know or understand. Diagnostics is the doctrine of seeing through: understanding through the things. This means not to stop at the phenomena as they appear, but look through them, with the assumption that behind or beneath the deceptive appearance, the true reality of a phenomenon lies: its essence.

Simone Weil says: 'it is not important to understand new things, but to learn to fathom, with patience, effort and method, obvious truths with your whole being' (1949: 223). Just like Baart, with this "fathoming" she refers to a deeper layer. Weil considers thinking - she calls it studying - as gymnastics for the attentiveness, but no more than that, because ultimately attentiveness is about something else. It is, according to Weil, about distinguishing between reality and illusion. The aforementioned "looking" is indeed a way to exercise the mind, but it is also about looking without attachment. For Weil, attentiveness is the 'suspension of the thought and the experience and allowance of the emptiness' (1949: 229). According to Weil, attentiveness is not a result of the will (i.e. the mode of producing'), but of a desire (i.e. the mode of 'waiting'). This is an important nuance: attentiveness comes down to really desiring, but not to trying to accomplish it. To Weil, it is about an attentiveness that is so concentrated that the "I" does play no role. In the words of Murdoch attention is an imaginative and normative use of moral vision that burns away the selfishness of natural human desire, leaving behind the purified desire or just and compassionate love (1970).

**Attentiveness that creates**

According to Murdoch and Weil, open attentiveness is about a way of seeing that 'imagines' love. Weil argues that when attentiveness is intense enough, it coincides with the ability of a human to "create". This creation is relevant from the perspective of care, as care is about getting to 'the good' in the relationship between caregiver and patient. It is not always clear what is good for a particular patient in a particular situation. However, this may crystallize in the relationship. The caregiver's open attentiveness can help giving shape to this good: slowly it can be imaged who he can be for the patient and what his attention should focus on.

Waldenfels (2004) also refers to this *creating attentiveness*. He states that attentiveness consists of certain types of actions and accidents ('being given') that must be created. These types of experiences do not exist in the world of physical things and processes, nor in the inner world

of mental acts. They must be "created" by "determining what is undetermined". Instead of intentionality joining "us" with "the world" (as per Merleau-Ponty's phrasing), Waldenfels describes a responsivity that exists between the "order" on the one hand and the "alien" on the other. Correspondingly, his focus is on boundaries, borders and limits: on thresholds of attention, on the twilight of order, on the human as a "liminal being" (2011, pp. 8-20), and significantly, on the dia, the "between words", as contained in the word dialog (ibid.). This applies to the doctor in the first example above: not only does he hear the words spoken by the patient, but he is also attentive to what is said "between the lines".

Husserl also emphasizes this indefiniteness or vagueness "in between". Creative perception means seeing and hearing something new by seeing and hearing in a new way. [...] Creative attention refers to a special dimension of experience that we characterize as *pathique* and *responsive* (Husserl in Waldenfels 2004). This means no experience can exist without somebody to whom it happens, whether it may be a case of pleasure, of pain, of joy or of sorrow. Vice versa there is no response without something to which or somebody to whom it responds. 'What takes place here on a deeper level precedes and exceeds every sort of sense and rule; it goes beyond intentionality and regularity. Whatever strikes or affects us does not possess any sense or follow any rule in advance, it only obtains a certain sense and a certain regularity by the creativity of our answers' (ibid). Husserl does not see creation as something like a pure creation which would transfer us straight into a world of imagination. On the contrary, 'creative responses transform and deform given forms in a way similar to how the Revival re-created the imagery of Greek-Roman antiquity' (ibid.).

To open up this deeper dimension, Waldenfels argues we need a special kind of responsive attentiveness that interrupts the progress of the natural experience and gives up what we take for granted. This does not lead us to what our experience means, but rather to what our experience is responding to. This applies to the doctor in the second example above. In letting the patient play with him a little, and in not being able to explain what he is doing and for what reason, he leads us to what his experience is responding to.

Merleau-Ponty (1945) writes about attentiveness as a transformative act. According to Merleau-Ponty, attentiveness can bring about a transformation of the mental field by adhering to turning points. Unlike a single mention of anything due to the importance of the subject, or the surprising nature of the object, Merleau-Ponty understands attentiveness as a new way of being present to things. Attentiveness is a transformation on the way it is aware of something. 'In attention, consciousness can become attentive and attend to being-in-the-world, to the presence

of the world and not merely to the present world at hand' (Sá Cavalcante Schuback 2006: 138). This transformative attentiveness then points at a rediscovery of things.

Verhoeven calls this 'wondering'. Rather than understanding this as something unexpected coming to us that we had never experienced that way before, he claims that wonder creates a transformation in which the previously experienced things can be seen in a new light. Attentiveness in the meaning of 'wonder' is a respite from ingrained patterns of perceiving, naming, thinking, and acting. Attentiveness therefore means a transformation in perception and knowledge.

In his book on the art of hunting, the Spanish philosopher Ortega y Gasset creates a type of phenomenology he calls *the hunter's attention*. He describes hunting as letting go of a focus. A hunter is someone who has learnt how to wait. The hunter has learnt to expect the unexpectable. This vision resembles Simone Weil's: the hunter's attention is not connected to anything that's already there either, nor is it the ability to respond quickly to surprising occurrences. For the hunter, attentiveness is related to the open indeterminacy of imminent events (Ortega y Gasset 1960). That openness is odd, because openness can only catch our attention when we divert our attention from the indicated objects. It is precisely at the moments when attention focused on fixed points is interrupted that open attention has a chance to break through.

In sum, attentiveness is neither a collage of outer mechanisms and internal acts, nor a scale leading gradually from passivity to activity. On the contrary, it is carried on by a radical kind of passivity. This sort of passivity proves to be more than the mere counterpart of our own activity and more than a diminished degree of activity. Responding means to start from elsewhere, from what is alien to us. While responding to the other's appeal we step outside ourselves.

**Attentiveness and mindfulness**

This sort of passivity is cultivated in the Buddhism-oriented movement of *Mindfulness*. *Mindfulness* recognizes the double event of attention (being affected by and responding to) and can be described as a non-judgmental presence in the here and now. It is used both in a psychotherapeutic context (e.g. in the treatment of anxiety and stress), and in a more ideological context (meditation inspired by Buddhism). *Mindfulness* has also been described as an art of living marked by an aversion to the hasty life. These forms of *mindfulness* are particularly aimed at the ego, the self and therefore their relevance for hospital care mainly lies in self-care. Research has not clarified whether practising *mindfulness* leads to, for instance, more open attention for care

recipients or to paying more attention when carrying out certain tasks. This could still be the case, because practising *mindfulness* can result in concentration, which in turn will result in insights (Hanh 1998). When it comes to *mindfulness*, two forms of concentration can be distinguished: the active form and the selective form. The active concentration exists in the here and now and is open to anything that presents itself. When selective concentration is practiced, the attention is persistently focused on one object of choice. This concentration creates an intense type of presence, which results in stability and calmness. The higher the level of meditative concentration, the more insights are achieved. Another important aspect of *mindfulness* is attentiveness. This can be focused on our bodies, our feelings, our minds, and the object of our minds. Just like concentration, the attentiveness is focused on the present moment, enabling us to make contact with things or other people. This leads not only to understanding, but also to new perspectives and transformation (ibid). Themes of a similar nature can be found in Benedictine spirituality (Casey 2005; Grün 2006; Derkse 2000). Both *mindfulness* and these Christianity-oriented ideas on living in attention are about permanently practising 'the respectful receptivity of the infinite other' (Baart 2008: 9).

**Attentiveness and unknowing**

When it comes to care, the point of the double character of attentiveness is that the caregiver, despite his lack of understanding, does not turn the gaze away but keeps watching. Attentiveness as described above is open and, to a greater or lesser extent, searches for an understanding of what the proper focus must be. It is both active and passive. Some forms of open attention do not even seem to pursue any understanding at all but advocate a kind of "un-knowing":

> Knowing is wonderful, but it is just a guiding means. Unknowing is a condition of openness. This unknowing in the intersubjective space of two people or people of two cultures allows others to be. This art of unknowing may enable a nurse to understand, with empathy, the actual essence of the meaning an experience has for a patient. This pattern of unknowing focused herein on the intersubjective whole between patient and nurse is applicable as well to learning in a more formal sense. To be open to learning one needs to posture oneself in a position of unknowing to hear a colleague, a teacher, a student. To provide and find openness is to be able to say, "I never thought about it that way," and at once experience the wonderment of coming upon an "unknown" (Munhall 1993: 125).

Open attentiveness means a certain unknowing, a kind of swinging with what happens and a loosening of the reins, with the assumption that the unseen will show. This seems to be against the rules of medicine, in which everything must be monitored and controlled. In some situations however, good care requires unknowing attentiveness that is not focused on results or goals.

**Attentiveness and understanding**

As stated before, we cannot always fully understand patients. In practice, not understanding often means that caregivers direct their attention toward something else, something they are able to place. However, the above literature shows that attentiveness is not necessarily connected to grasping the other's point of view. We do not have to understand patients in order to be attentive to them.

Just like patients, no experience is the same. Describing an experience is difficult. Once we give words to the experience, we have to deal with an inevitable loss of meaning: "When you say the word flower, you have already lost the bouquet," the poet Mallarmé writes. Words like to stick, and do not allow escape. Rational, descriptive knowledge describe reality so much that there are also aspects that escape this described reality; there is too much firmly fixed to allow for a more comprehensive meaning (Bos 2011).

It seems to go against the current organization of health care, since everything needs to be determined precisely, but good care cannot do without indeterminacy. We should not just focus on the patient experience, we should also realize that we cannot grasp it fully, and create a kind of reservation. At the same time, this reservation should have a place in our thinking and evaluating of the quality of care, and should not be stashed away.

**Discussion**

How can caregivers be attentive to patients despite of the impossibility of fully grasping their experiences? This paper elaborated on attentiveness, and discussed the meaning of focus or understanding defined as determination. It concluded that attentiveness can also be undetermined, unfixed, or pending.

Much has been written about patient-centredness, patient experiences, patient lifeworld, and so on. The claim is that these kinds of research may help caregivers becoming more sensitive to what is at stake for patients, by taking up an *emic* point of view. Of course, this is a very good

idea. But there also something else going on, which partly contradicts that: it is impossible for caregivers to fully understand patients. When it comes to attentiveness in health care, we need to thematize this impossibility as well: the emptiness, the lack of understanding.

Strikingly, Blanchot (1997) writes that some experiences ask for "inattentiveness" - negligence and absentmindedness - rather than attentiveness. His concern is a special kind of inattentiveness. Not an insensitivity that only betrays contempt, because such insensitivity might just be about an "I", who imagines he is the centre of the universe. The inattentiveness Blanchot writes about is more passive, less calculating, and less aggressive. In this carelessness it is not the "I" that is key. On the contrary, the "I" is exposed to a passion for the passive, for not-doing, for negligence. This passion for the passive is characterized by the fact that, as Blanchot puts it, the eyes remain open without them seeing ('les yeux ouverts sans regard'). The "I" disappears. There is no one who wants to grasp the world anymore.

We think the literature that presents patient experiences and thereby claims to provide insight or understanding, partially falls prey to the problem that is precisely identified by the authors. The more we try to get a grip on the experiences of patients by translating it into 'knowledge about patients', the more it will actually escape our understanding. If we want to do justice to the experience of (sick) people, to their unique experiences, we might have to focus on the impossibility of grasping the other's point of view, rather than on the urge for understanding.

The growing interest in research into the experience of patients is not the same as being attentive to patients, as long as the research is seen as a tool to be more attentive to patients in health care. Attentiveness is not something we have, and not something we can shape arbitrarily. Attentiveness has us and shapes us. We can often direct our attention, but it will always be characterised by a certain level of uncontrollability as well. Our attention surpasses our own projects, just as it surpasses the various techniques and practices by which our attentive behaviour is modelled.

## Conclusion

Does the current constant urge to understand the experiences of patients threaten the attentiveness to patients? We have made it clear in this paper that, in our view, it is not the question whether patients will still be seen in the future. There is no reason to fear that attentiveness will disappear. There is rather a danger that the desire to "make" attentiveness, will cause attentiveness to be understood as combating ignorance. As health care professionals, we must not attempt to understand patients fully. Conversely, understanding is, in the vision that we

have developed in this paper: being attentive to what comes into existence because of the fostering attentiveness; to what shows itself to the extent that attentiveness seeks the mode of 'letting things happen' (receptivity), and is not imposing functionality but respecting otherness. Only in this meaning, we avoid that out of the fear of being confronted with a lack of understanding, we fill gaps with our own impressions and thereby take the position of the patient. 'Reflecting on our own experience to understand the other is balancing between "ego-centrist" non-understanding and empathetic understanding of the other in terms of ourselves' (Van der Geest 2007: 9). We carry the experiences of being sick, of uncertainty and dependency, with us in our bodies, in our family ties, in our culture, and in our language. It is in those places where we experience an understanding of what cannot be understood. The desire to be attentive to others will report itself from those places. But only if we can leave room for it, and if we do not fill this space with well-defined views about what should be understood, and for what sense and benefit.

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# 8

# Discussion

# 8

# DISCUSSION

This thesis deals with the dynamics of attentiveness in care practices. I have discussed caregivers' attentiveness by analyzing empirical data obtained from participant observation at an oncology ward of a general hospital. My main research question was: what does attentiveness look like in actual care practices? And how can we understand the attentiveness we see, or miss? In this concluding chapter, I reflect on the main findings of this research in relation to the objectives outlined in the introduction: gaining a better understanding of attentiveness in the hospital oncology practice, and finding starting points for exploring how attentiveness as we see it can be stimulated and maintained in order to contribute to good care. I will then consider several methodological issues of this study.

**Attentiveness as core business in healthcare**

Attentiveness is a very important component of good care, in many cases it is even what care is based on. However, there is a lack of concepts enabling thinking about attentiveness in a care ethical way, and of theories to support it. With the analyses in this thesis, I have tried to compensate for this deficit. Attentiveness is a neglected subject that is generally addressed in a primitive way. That is, by equating it with empathy, concentration or proper treatment. From a care ethical perspective, care turns out to be about recognition, and not primarily or only about healing. There is much conceptual developmental work to be done in this area; the analysis of attentiveness (the different forms and types, underlying cultures and experience of discretionary space) has only just begun. Attentiveness needs a conceptual framework to enable us to think about it and work with it. This study provides a foundation.

One must no longer pretend that attentiveness is something that hospital caregivers only get to if they have the time, or something they can outsource to social workers, psychologists or patients' family members. In the currently dominant definition from Machteld Huber (2014), health is more than physical functioning; it also has a psychological, social and spiritual dimension and it refers to quality of life and social participation. Hospitals focus on the physical areas of health and well-being. However, this thesis shows that caregivers in hospitals need to be

aware that people are more than a disease, and that their sick bodies are connected to those other areas of health and well-being. This does not mean that hospital caregivers must also be able to intervene in those areas. It could very well be that other people, with different expertise, are more suited for that task. This thesis shows that caregivers should not close their eyes because they "can't do anything about it". They should try to be receptive and attentive to what matters to someone, even if they cannot change anything about it.

Critics suggest that attentiveness takes time and that more attentiveness will thus increase the costs of care. This thesis shows that this is not necessarily the case. Firstly, recent developments show that taking more time can actually reduce costs instead. For example, the Dutch insurance company VGZ and the Dutch Radboud UMC hospital state that caregivers cannot properly determine what is wrong with a patient during brief conversations, and as a result, they too often decide on a treatment that is not really necessary (De Volkskrant, December 11, 2015). Therefore, during the coming years, VGZ will provide the Radboud hospital with the space to devote more time to consultations, and to save money by not carrying out unnecessary surgeries. In return for that, the hospital has entered into a multi-year contract with VGZ.

Secondly, this thesis shows that attentiveness does not necessarily take more time. It is a misconception that all caregivers must give extra personal attention in the form of pleasant conversations or holding hands. Attentiveness may also be given *within* the caring or medical procedure itself. Therefore, it is essential that a procedure is not performed on automatic pilot, but that it is focused on *this* particular human being. Patients can be perfectly satisfied without caregivers asking them about their personal lives. As long as they are washed well, with attention for their specific physical characteristics and washing-needs, that's enough attentiveness and recognition. From this perspective, it might indeed be possible to save money.

Ab Klink, board member of insurance company VGZ and former Dutch Minister of Health, states that "efforts to save time are making care more expensive. The conversations between doctor and patient are becoming shorter. And if you are a doctor, you still want to do something in such a short time, so you quickly opt for treatment" (ibid.). What this thesis adds to this, is that the problem here is not only lack of time, but the fact that doctors firstly concentrate on curing the sick body and secondly, they are quite eager to *do* something, to intervene.

*An open, inclusive conception of care*

The current study shows that being attentive is strongly influenced by the culture of caring. Modern hospitals see themselves as institutions designed to heal and alleviate, and consider the

biological, physical side of the patient as their core business. The extent to which caregivers are either locked in the logic of such hospitals, or feel free, largely determines how attentive they are. This mechanism of managing socio-institutional enclosure provides a good basis for analyzing attentiveness in actual care practices. This thesis shows that caregivers who have an open, inclusive conception of care, who do not only look at the body but also at the person of the patient and who steer their care accordingly, can provide a counterbalance to socio-institutional enclosure that defeats free, relational attentiveness as a component of good care. This promotes the quality of care experienced by patients.

It should be noted, however, that the attentiveness of caregivers focused on the biological, physical side of the patient, is extremely important. The by caregivers carefully rehearsed professional role behavior, aimed at giving maximum attention to the disease, to fight it or to relieve pain and discomfort, contributes greatly to the quality of care. Protocols can help to keep the attention focused. This thesis shows that this is only part of the story, but it is a very important part.

If caregivers want to learn to be attentive in a care ethical way, it seems they must especially make sure to *unlearn* things. Caregivers must be careful with understanding and interpreting. It appears to be important for them to reflect on their own judgments and personal limits, to search space within the frameworks of routines, habits and professional obligations, to consult colleagues and to think about why they view something as good or bad. It is important to be interested and surprisable. Sometimes it is thought that being attentive is the same as communicating well, but that is not necessarily true. Of course, it is good to talk to patients, but that's not the point. Good attention, such as alertness and interest, requires a certain authenticity. *Feigning interest* is not *being interested*. Attentiveness in the meaning of *behaviour* can be learned - by exhibiting behaviour that people interpret as interest - but no one can simply learn to *be* attentive. The point is to be open, to unlearn things, to make room, and to then see what happens. As the essayist Henri David Thoreau said: 'It is not what you look at that matters, it's what you see.' In learning to be attentive and awake, it is also important that caregivers collectively reflect on their daily practice and the choices they make. Good care requires knowing why you are (not) doing things and what you strive for in your practices of care for patients. After all, it is not only about what is possible in a situation or about what should happen, but also about what caregivers themselves find desirable and valuable in care. Consciousness, as well as being able to make their own professional values and goals explicit, appears to allow caregivers to properly explain to others why they pay attention to something or why not. This enables them to direct and justify their actions, acquire authority and discuss their choices with others (colleagues, hospital

management, patients, and relatives). In turn, this helps the caregiver, despite the socio-institutional enclosure, to experience some space to be open and receptive to the patient. At least we have seen that in the same conditions (of socio-institutional enclosure), some caregivers are able to be attentive in a care ethical way, and others are not. This means that the conditions are not absolute and that there is a relevant personal factor in being attentive (learned or otherwise acquired).

*The political dimension*

In the introduction to this thesis, I stated that this study would also have an eye for the political dimension of attentiveness. This means that I did not only look at individual caregivers, but I also took into account the context and possible power effects. Tronto, amongst others, has developed the political ethics of care as a theoretical framework, and more recently, as a framework for democratic care. For this purpose, Tronto added a fifth phase to her descriptive phases of care (2013). She presents the fifth phase, 'caring with', as a more political dimension. Broadly understood, this idea is similar to the values of solidarity or pluralism. Unlike her original four phases of care, 'caring with' is explicitly normative; for Tronto, this fifth phase does not merely describe the nature of democracy, but also highlights a condition of its survival and a means for evaluating its commitment to justice, equality and freedom for all. A consequence of this is the creation of a just, human, and caring society. Tronto shows that care practice cannot be conducted in accordance with the moral expectations of its stakeholders under unjust circumstances, marked by unequal status and penetrated by social relations of domination. Garrau (2014) speaks in this context of *institutionalized indifference*. She explains how care is socially devalued and distributed to subordinate social groups, thereby exempting dominant groups from caring activities. These dominant groups can indeed maintain the fiction of their independence and deny their own vulnerability and the importance of caring activities, allowing for the constitution of autonomous subjectivities and maintaining social cohesion. It is this mechanism of systematic transfer that contributes to maintaining relations of domination that Tronto called the indifference of the privileged (2013). By uncovering the effects of this *institutionalized indifference*, Garrau invites us to recognize attentiveness as a core democratic value. Whereas she describes institutionalized indifference as a vehicle of inequality and domination, she sees attentiveness as 'a vector of inclusion and adequate response to the complexity of human affairs' (Garrau 2014: 67-68, my translation).

The political dimension in this thesis is particularly evident in the description of socio-institutional enclosure. Caregivers with an open, inclusive conception of care, who do not only

look at the body of the patient but also at the person they are, could provide a positive counterweight to this socio-institutional enclosure. Therefore, it appears to be essential that the patient is seen as a person-in-relations. Relational care is required as it is in the relation that the caregiver learns who the other is, what is important in their life, what is at stake at this moment, and what could possibly be appropriate and meaningful to pursue. Caregivers can only be attentive and work relationally if attentiveness is cultivated in the organisation. In order to improve something about attentiveness one should not (only) push the individual caregiver, but also look at processes within the organisation. If caregivers are snubbed or made into production units by their superiors, they can hardly be attentive to patients, at least not in a care ethical way.

Another question that should be asked is who the caregiver is. Caregivers are not inanimate instruments giving care, they are persons who take their personalities to their caring relationships. Does the caregiver like jokes? Do they get nervous quickly? Have they experienced things that help them understand you better? In proper care, it is not just about professional relationships between caregivers and patients, but also about relations between sick and healthy persons, or between two people who both worry too much. Once a relationship has become more than just functional, and someone presents themselves as a sensitive, attentive and touchable fellow human being, the 'chemistry' can arise that can make care so good. This occurs at times when professionals just step out their professional role. An example of this is when a nurse shares with you what she finds important in life, when it seems as if your oncologist is a friend, or when the ward doctor indicates that he also has difficulty coping with a certain situation. When a caregiver shows himself as a person, the patient is more inclined to do the same. Only if there is such an inclusive view on care at all levels of the organisation, caregivers will be able to provide a positive counterweight to the socio-institutional enclosure, and what really matters can come to the fore. Of course, the political dimension reaches far beyond the organisation and management of the hospital. As Tronto argued, in order to account for good care, society should be a caring society. Even though I myself have seen how society-wide mechanisms influence the experiences of caregivers and patients through healthcare practices, this far-reaching analysis falls outside the scope of this thesis.

It is important to observe that in this thesis, socio-institutional enclosure comes to the fore as hindrance for being attentive, and is therefore quickly regarded as something bad. However, socio-institutional enclosure also appears to be something that is a prerequisite for care. Caregivers are continuously supporting this culture of enclosure and developing it using processes of socialisation. This thesis describes several typical working days of doctors and nurses in hospital oncology care. These descriptions provide some background on this theme by

showing differences, not only within several occupational groups (specialists, doctors, nurses) and between their positions in the hospital, but also, in particular, when it comes to moments of socio-institutional enclosure. Rather than to simply reject the socio-institutional enclosure, future research should make an effort to further understand its logic and the need for it. Why does care need it? Why is it important for caregivers? Do the implications of socio-institutional enclosure make them better caregivers? Is it essential for the organisation of the care work?

## Methodological reflection

This section discusses the main findings in the context of methodological strengths and limitations. I will focus on a few general issues as much has already been discussed in more detail in earlier chapters.

*Evaluating the grounded theory*

A grounded theory must be evaluated in three ways. It is about judging the theory, the research process used in developing it, and deciding if the methodology was appropriate (Bluff 2005). Reasons for choosing the grounded theory approach need to be made explicit. Chapter 5 and 6 deal with these issues. Chapter 4 takes a more descriptive approach in presenting a first 'unveiling' of the empirical observations. It sketches the context of the empirical study and shows some first impressions of how attentiveness could be understood in this setting. Morse (2001) states that it is essential to provide such a detailed description of the context in which the study took place, yet she acknowledges that many of the research articles sent to her for publication fail to elaborate on this important component.

Chapter 2 of this thesis shows that the research question was quite broad. The data collection and analysis in later chapters demonstrate how several important issues emerged and how the study became more focused. The method sections in chapter 5 and 6 explain how sample selection took place. The results sections explain how concepts were derived from the data. The quotes and the figure in chapter 5 and the table and the figure in chapter 6 provide some transparency about how categories were formed and why certain categories and sub-categories were linked together. The fourth intermezzo in this thesis is an extra example that elaborately illustrates how a piece of raw data ends up becoming part of the theory.

As grounded theories are based on data, they should represent the social reality as perceived by participants. In other words they 'fit' (Glaser and Strauss 1967). This will not only be recognizable to the participants when they review the findings, but also to others who are

familiar with the social setting (ibid). Understanding the theory is also important if it is to be used effectively. Glaser and Strauss suggest that a grounded theory should 'work' and 'be relevant'. It should explain what is actually happening in a particular setting and it should predict what will happen under certain conditions. I believe this study meets these criteria. It provides a framework that expresses how attentiveness comes to the fore in actual oncology care practices. As it can largely predict what will happen under certain circumstances, it also provides starting points for what can be done to enhance the quality of care and it thereby provides guidelines for action. Meeting these criteria implies that it is potentially useful. Its findings cannot be generalized to an entire population but may have meaning for others in a similar setting (Strauss and Corbin 1998). Likewise, a grounded theory study cannot be replicated, but if another researcher would follow the 'audit trail' described in chapters 5 and 6, the theoretical explanation for the phenomenon should be similar.

*Reflection on the position of the researcher*

Who is the researcher and how did she direct her gaze? Obviously, the focus of the researcher is relevant in a thesis on attentiveness. In grounded theory, as in any other type of research, it is essential to reflect on how the researcher's perspective is intertwined with the data. Grounded theories are often criticized for their 'groundedness' or 'theory', or both. In such cases it is unclear how the theory is based on empirical data, or how the data are based on the theoretical perspective of the researcher. This issue is dealt with in the method section of chapter 6. The latter refers to chapter 2, which deals with the literature study on attentiveness and sets forth which perspectives were examined, and how the different insights were used. Chapter 3 explains the background of this work that 'sensitized' the researcher, and it zooms in on the implications of lending from and mixing various disciplines and backgrounds. Yet, it also answers the question why this study can be considered as having a care ethical perspective.

Of course, a researcher is more than her theoretical perspective. Both in choosing and reading literature and in collecting and interpreting the data, many choices and considerations are undoubtedly based on preferences of the researcher and her supervisor, as well as on the fact that they are better equipped in some fields than in other. It is important to mention this. Many scholars describe the social sciences as resulting largely from the 'art of interpretation'. Perhaps the most important tool in the practice of this art is the researcher themselves. Qualitative methods rely on 'standardized' instruments and methods much less than quantitative methods. Thus, the researcher is positioned quite closely to raw words and real life, and the researcher as a 'person' plays a more obvious role at all stages of research. This does not mean that researcher

characteristics are not pivotal to every stage of quantitative research as well. But while quantitative research attempts to minimize or even obscure these issues through standardized protocols, qualitative research applies an alternative strategy by explicitly accounting for subjectivity. While I share Thompson's reluctance 'to put myself in my academic writing and thereby lose some of my own and my family's privacy' (Thompson, 2005: 22), I think that some reflection on personal and professional characteristics is appropriate for the sake of transparency and validity.

I have been engaged with care for a longer period. I was trained as a cultural and medical anthropologist and as a remedial educationalist *(orthopedagoog)*. My thesis subjects have successively been: organ trafficking and globalization, family relationships and well-being in single-parent and two-parent families, practices of child fostering in Ghana, and the development of child psychiatry in the Netherlands. During my studies, I did an intensive internship in a children's psychiatric hospital. In addition, I had a student job in a mental health care institution. However, before I started this research, I had no professional experience in general hospitals, nor in oncology. I had never been hospitalized myself. These experiences (or lack thereof) definitely affect what I have studied and written, though it is impossible to indicate exactly how. Why do some personal factors matter and others do not? Can everything be expressed as flowing from certain autobiographical precursors (Thompson 2005)? Does it matter, for example, that I was also trained as a caregiver? My participants sometimes referred to my own experience, using expressions such as 'You have worked in healthcare yourself, so you must know how it is'. Does it matter that, while I conducted my fieldwork, some relatives were diagnosed with cancer? Does it matter that I was hospitalized for one week during the last year of writing on this thesis? Does it matter that I came from a different part of the country than my participants? While realizing that many factors may indeed matter with regard to how I conducted the study, it is impossible to consider these and all other possible relevant autobiographical factors, or to be aware of all the subconscious ways in which our assumptions shape our approach to research (Green & Thorogood 2004).

*Ethical considerations*

Informed consent, confidentiality, and not doing harm are key principles of ethical practice in social science research. In the previous chapters, I have described how I handled ethical issues: how consent was given by the medical ethics committee of the hospital and research informants, and how I guaranteed confidentiality to the people participating in the study. Though one may conclude I have therefore fulfilled my ethical responsibilities as a researcher, in this section, I will

reflect on some of the complications that may arise when applying these commonly shared ethical principles to a study such as this one, and how these intermingle with the researcher's personal considerations.

Informed consent basically means that individuals should by no means be coerced or persuaded into being involved in the study, and that their participation should be based on a full understanding of its possible implications. Researchers have pointed to the problematic side of this ethical principle, in particular when doing observational studies in clinics (Green & Thorogood 2004). As data in qualitative hospital studies are collected from a range of often changing informants, and on different occasions, it is impossible to fully inform all participants in detail about the aim of the study and ask for their informed consent. In this study, the heads of the departments, and the caregivers participating in my study were fully informed and their permission was asked before participating. However, this was much less strict for the other personnel and for the patients I observed only once. With regard to the oncology personnel, they were all briefly informed about my presence and the study objective.

At the introductory stage, I always asked individual doctors and nurses permission for being around them while they were doing their work. In principle, they could decline my request, but in fact they had little space to do so as their superiors had consented to the study. One time a nurse asked if I could choose someone else to observe that day, because she was having a bad day. In the introductory stage, one of the oncologists denied me access to his consultation room. He explained that he was already experiencing enough stress, and the presence of a researcher would only add more. I did not insist. However, when I followed some patients in their treatment later on, it happened that I ended up in the consultation room of this doctor anyway. I also tried to see him at work during his rounds on the ward, which he tolerated.

It was slightly different with patients. For instance, the ones who were at the ward or the outpatient department or whose consultation I attended during their visits at the policlinic, were sometimes quickly asked whether they agreed to my presence at their doctor's consultations or during caring activities, while they were informed about my study objective as briefly as in one sentence. In some cases, I did not and still do not consider this as a problem, as there were so many people in white coats around them anyway. One of the oncologists told me the same when I asked him. 'There are four of us already, it does not change anything if there is a fifth'. In other cases, for instance when I helped a nurse wash a patient, the short introduction made me feel uncomfortable. This was also due to the fact that on such occasions, apart from my intentions to help the nurse, I was the only 'observer' present. During doctors' rounds for example, the interns present there were only standing around the bed and observing as well. It was different when I

was with one of the nurses. I always took some time to elaborate on my presence. And with every specific activity (e.g., closing the curtains before undressing), I asked the patient whether they agreed that I stayed.

When starting the fieldwork, I was offered a white coat to facilitate my presence at the department. Wearing a white coat makes you belong to the clinic staff, it gives you a place in the hospital system and you become one of them, and as such it justifies your presence. The doctors and nurses insisted that I should wear the coat and I certainly used this opportunity. When I was with doctors I wore a doctors' coat, when with nurses I wore a nurses' jacket (not the pants). I wore a badge with 'researcher' written on it. There were times, however, when wearing a white coat made me feel very uncomfortable. It felt as if I had, in a way, misled both the patients and the caregivers who were not familiar with my position. On the other hand, not wearing a white coat might have made participants consider me much more of an intruder. Moreover, creating the appearance of the clinic staff also invoke positive reactions. Some patients told me they liked it that the hospital performed research on such a topic. In retrospect, it would have been interesting to consider wearing a different hospital uniform, e.g. a coloured jacket that nurses wear at the children's ward, or a surgery uniform. In this way, one could suspect that I belonged to the hospital, and at the same time, it would immediately raise questions which would provide the opportunity to explain my position.

Other ethical issues related to the choice whether or not to intervene in a situation in which the interests of the patient were contrary to the interests of my research. For example, situations in which a patient was insecure or angry because there was something they did not understand. Sometimes I would have knowledge that could reassure them, because I had attended their conversation with the doctor and had been able to listen better, or because I had obtained the relevant information in another way. It was up to me whether to tell the patient what I had understood (for their sake) or not (for the sake of my research). Similar situations included those in which I went along with the nurses, e.g. to wash a patient, and in which I thought they showed little consideration for the patient. At such moments, I felt inclined to step in, but I sometimes did not do this because I wanted to affect the situation as little as possible, and moreover, I was not sure whether I were right. At other times, I chose to intervene, believing this was in the interest of the patient, and I tried to reflect on it with the caregiver afterwards. This both contributed to the confidence between the caregiver and me, and it provided information on the caregiver's motives.

*Limitations of the study*

In this section I will describe and reflect upon the main limitations of this study which is also meant to evoke (methodological) discussion and may lead to further research.

First, this grounded theory of attentiveness can in some respects be regarded as static and less dynamic and might raise the question whether its findings have been oversimplified. This refers to situations in which different types of attention rapidly succeeded each other and in which it was unclear what 'drove' the attention after all, or what the dominant type of attentiveness in that particular situation was. For a sick person, for example, the highly focused attention to the diseased body may be very beneficial. This is simply because the attention is exactly focused on that part of the body that is causing the patient's misery. For the patient, it is great to know that he can 'outsource' this to a skilled physician. At that moment, that is exactly the amount and type of attentiveness the patient needs. Other forms of attentiveness would be unnecessary as the fact that they fell sick makes them 'be' their sick body.

Reflecting on this situation I would say that there are two possible explanations for this situation. First, the concentrated focus on the sick body is legitimated by the caregiver's relationship-based attentiveness. The task-orientedness is embedded in the person-orientedness: what the caregiver does, and how and to what extent they do it, depends more on the patient and on what the caregiver believes they need based on the relationship between them, than on the disease itself. In the second explanation, the caregiver is completely focused on the sick body, led by a purely task-oriented focus and thereby avoiding all stimuli that might distract his attention. According to this explanation, the fact that this works out well for the patient would merely be a happy coincidence. We know that the outcome for the patient is good, but we need more information to decide how to identify the type of attentiveness.

This example shows that while this study has a care ethical character and emphasizes on the normativity of attentiveness, the grounded theory presented in this thesis does not simply explain how a particular situation can be labelled as 'good' or 'bad' from the perspective of the patient. The different types of attentiveness are neither directly linked to the outcomes for the patient, nor vice versa. From a care ethical perspective, one would encourage relationship-based attentiveness, since this includes an integrated relational 'check'. That does not mean, however, that task-oriented attentiveness, such as hurried or disciplining attentiveness, can never turn out for the good as well.

This brings us to a second limitation. On several places in this thesis I have presented quotes from my observation material. In some respects, these could be regarded as mainly negative examples or examples of poor attentiveness. This can be explained by the fact that this

study started by questioning the very meaning of attentiveness: what does it look like in actual care practices? I have deliberately approached attentiveness as a diffuse concept with many possible meanings for a long time. As a result, the issue of the quality of attentiveness was postponed. In order to gain an insight into the identity of attentiveness, it was necessary to observe openly, to compare cases, and to exclude certain types or manifestations. I looked as openly as possible and my attention was drawn to situations that struck me for some reason. In this way, certain kinds of attentiveness could be identified, e.g., as concentration on the treatment. Gradually, while more sensitizing concepts and a terminology to describe attentiveness emerged, it became possible to distinguish between differences in nature, intentionality, effect, and quality. When contrast arose, I could also identify the care-ethically adequate examples of attentiveness. However, in the construction of the grounded theory of attentiveness, I mainly worked with examples of poor attention, as they helped me figure out what attentiveness was (or was not). Although it was epistemologically inevitable, I acknowledge that this thesis mainly consists of examples of poor attention. This is a limitation, in the first place because good examples and a more balanced presentation of quotes are instructive. Secondly, in retrospect, it would also have been interesting to further study attentiveness from this perspective.

**Concluding remark**

In the prologue to this thesis, I introduced a photographic work from Liza May Post that really impressed me. In this picture, a woman is depicted alone, in the bleakness of an institutional space. But more importantly, we do not really see her. The woman seems to be caught in the tension between visibility and invisibility. She is a person in an institution who is only seen because she is 'absent'. Because she differs from the corporate norm. The invisibility of her face makes us feel powerless: the possibility of getting to know her is taken away. Fortunately, this is different in the real world. Even though not everyone opens up easily, there is the opportunity to see each other.

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# SUMMARY

**Chapter 1: Introduction**

In everyday language, in the opinions of my study participants, in the public debate, and in scientific literature, I encountered a dichotomy in thinking about care. On the one hand, there is the medical-technical[15] side of care, and on the other hand there are the social aspects of care. Attentiveness is considered as belonging to the latter. The participants in my study share the opinion that care should in the first place be medically good, and second, it is considered important that caregivers are attentive. Several caregivers mention that a caregiver can, without giving attention, indeed be a good caregiver: 'A good doctor for sure. He just might be less kind to patients' (a physician). The social side, to which attentiveness belongs in these views, is considered a pleasant side effect; an extra that can make caring more beautiful. In contrast to this view of attentiveness as an additional social part of care, this study departs from a wider view on attention. This is a direct result of the use of a broader vision on care: care is perceived as more than only competent and communicative. This chapter introduces the reader to the ethics of care, and the important role it attributes to attentiveness. Then again the concept is broadened, as attentiveness is not only the first step towards care, it can have a socially-enclosing meaning and as such it may *be* care.

Despite its importance, it has hardly been examined what attentiveness is in professional health care practice, and how it is influenced and reworked by culture and other social realities in particular local contexts. This thesis seeks to understand attentiveness in care empirically and theoretically, without fixing its meaning. The examples and explanations attempt to encircle the meaning of attentiveness, but also leave space for what emerges 'between the lines'. It aims at providing starting points for analyzing attentiveness in care. It studies (mainly) doctors' and nurses' attentiveness at the oncology department of a general hospital.

**Chapter 2: Attentiveness in care. Towards a theoretical framework**

The literature on care provides no unanimous definition of attentiveness. In order to examine the functioning and aspects of attention, we need a comprehensive clarification of the concept: how is attentiveness understood in this study? The study has an exploratory nature. This means that it

[15] or nursing-technical

is not known beforehand what attentiveness is and how it works in the hospital - rather, this is precisely one of the research questions. Yet, to examine attentiveness in actual care practices, we do have to sensitize ourselves for the phenomenon in order to avoid overlooking relevant things. This chapter provides the sensitizing concepts necessary to study attentiveness in actual care practices. It discusses the existing literature on attentiveness from different angles, by looking at the meaning of attentiveness in psychological, philosophical, and spiritual literature. By analyzing these meanings from our care ethical interest in it, we developed a for this study relevant conceptualization of attentiveness.

Three themes stand out as major issues in our thinking on attentiveness in care. Firstly, the importance of relations is emphasized. This means that an empirical study of attentiveness in a health care setting should look at establishing relationships. Secondly, we stress the importance of attentiveness as a practice that can create a space in which a relationship may arise. Attentiveness may have an instrumental function, which dominates in contemporary health care, but attentiveness may have a beneficent meaning in itself as well. Thirdly, it is important to pay attention to the structural context in which practices take place. This means that one should consider and search for the possible ways in which the context of the hospital influences the crystallisation of attentiveness in practice.

**Chapter 3: Demarcation of the ethics of care as a discipline. Discussion article**

This chapter zooms in on the use of an ethics-of-care perspective while using an intradisciplinary framework. The inspiration for this article springs from our discovery of shared feelings of tension in using several disciplines while working in the ethics of care without being trained as an ethicist, and to find a disciplinary niche. As we each study a topic that appeared to be important from a care ethical perspective but that is not yet fully developed by it, we take advantage of knowledge from other disciplines. However, these disciplines all have their own traditions, natures of existence of what is under study, and epistemological and methodological frameworks. Therefore, the challenge we face is to understand, and, at least partially, integrate and mix the other frameworks with our own. Subsequently, since lending from and mixing varying disciplines and backgrounds carries the risk of losing the heart of the matter, we need to ensure to retain a distinct care ethical discipline. This may be supported by an open and critical debate on the criteria and boundaries of the ethics of care. As a contribution, this chapter proposes a tentative outline of the care ethical discipline. What is characteristic of this outline is the emphasis on relational programming, situation-specific and context-bound judgments, a political-ethical

perspective, and empirical groundedness. It is argued that the ethics of care is best developed further by means of an intradisciplinary approach. Two intradisciplinary examples show how within the frame of one discipline other disciplines are absorbed, both with their body of knowledge and their research methodology.

**Chapter 4: Attentive care in a hospital. Towards an empirical ethics of care**

How does our use of an ethics-of-care perspective interact with our interpretative qualitative study? This chapter includes a first 'uncovering' of the empirical observations. Attentiveness is shown to be part of the core business of medicine. However, it has many facets, and not all of these are equally present in hospital care. It becomes clear that attentiveness can only have its good meaning and effect if it is the right kind given at the right time. Caregivers frequently succeed in showing the proper attention, yet this is often done tacitly. Attentiveness is not an easily accessible subject matter, and caregivers do not always use the term 'attentiveness'. It becomes clear that attentiveness comes by *seeing* the other. At the same time, one can never see another person in his or her entirety; attention therefore always means reduction. What stands out, however, as a major finding of these data is that when a patient feels seen, or understood, the caregiver's attention is focused on what the patient wants it to be focused on. This means that patients benefit from *shared* attention. Furthermore, a caregiver may help a patient by being transparent about the issue on which the attention is focused. This softens the fact that attention can never be directed at everything at once. When the caregiver is more open and transparent about the gap between what is seen and what is focused on, the patient may more often experience receiving attention.

**Chapter 5: The components of attentiveness in oncology care**

This chapter presents a descriptive model of attentiveness in practice. The development of a descriptive model precedes and enables the method of constant comparison as part of the grounded theory approach. Furthermore, as the descriptive model comprises the components of attentiveness, it provides caregivers with opportunities to analyze care situations from the perspective of attentiveness and reflect on them.

The analysis shows that a descriptive model of attentiveness comprises a coherent set of the clusters perception (A), object finding (B), and space for attentiveness (C). Perception (A) covers the caregiver's perception of the patient. It contains both perceiving *facts*, i.e. the cognitive

processing and interpretation of what someone says, means and thinks, and perceiving *emotions*. This leads to a certain willingness to attend (A'), implying a practical as well as an emotional and a moral willingness. Experienced space for attentiveness (B) is about the struggle to be able to be attentive. It is firstly about anticipating to the patient, such as wondering how far one can go and what things should the caregiver stay away from. Secondly, it contains finding space in yourself, meaning asking questions like whether you are strong enough to do something. Thirdly, the experienced space depends on the systemic context or the institutional organization of the care containing issues like rules, protocols, professional expectations, collegiality, and so on. These factors culminate in possibilities for attentiveness (B'). The cluster 'object finding' (C) is a central figure in the model. It is about finding an answer to the following question (although this often happens preconsciously): 'What am I actually looking at?' 'Do I understand what needs my attention?'. This finding of the object of attention leads to (a certain degree of) adequacy of the attentional object, adequate from the patient's perspective (C'). Through e.g. processes of divergence it may occur that an object is determined that is inadequate, because the expectations of the patient and the actual attentiveness of the care provider differ.

**Chapter 6: Managing socio-institutional enclosure. A grounded theory of caregivers' attentiveness in hospital oncology care**

This chapter presents the grounded theory of attentiveness that arose from this study. Our data show nine types of attentiveness, which are characterized by a certain goal and a strategy to achieve that goal. Some of these types may contribute to good care and should be encouraged. However, attentiveness may be deployed for a specific purpose. It is normatively charged and its outcome for the recipient may not always be good. Attentiveness derives its value from the underlying goal. What attentiveness is focused on determines whether it is well-doing. For example, something may be a clever surgery, but does not necessarily have to be good care. These findings differ from other studies, in which attentiveness is understood as something good by definition.

This chapter shows that two factors are decisive when it comes to explaining the occurrence of the different types of attentiveness. The first factor refers to the question whether the attentiveness is person-oriented or task-oriented: e.g. is the caregiver's attention focused on the cancer or on the person who has cancer? The second factor concerns the role of attention for care in the view of the caregiver. This appears to vary from attentiveness making care possible to attentiveness making care impossible. The significance of socio-institutional enclosure emerged as

a key theme within the findings. This concerns the space a caregiver may or may not experience to break free from the preponderant institutional orientation towards the physical body of the patient. At the intersection of the influence of socio-institutional enclosure and the substance of the caregivers' concepts of care, three cultures are found that comprise the different types of attentiveness.

**Chapter 7: How can attending physicians be more attentive? On being attentive versus producing attentiveness**

During the analysis, we have found that, although we can understand and explain many things, it seems that attentiveness always escapes the analysis partly. This observation, the inexplicabilities coming forward in the analysis, is the reason for this chapter. We propose that this inexplicable nature is not only an unavoidable element in the analysis, but also an indispensable ingredient of good attentiveness - and therefore, there should be space for it in healthcare.

In current discussions on healthcare that must be attentive to patients, the emphasis is on understanding patients by obtaining as much insight into their experiences as possible. Consequently, more and more studies focus on patient-centredness, patient experiences, patient lifeworld, and so on. The claim is that these kinds of research may help caregivers becoming more sensitive to what is at stake for patients, by taking up an *emic* point of view. Of course, this is a very good idea. But there is also something else going on, which partly contradicts that: it is impossible for caregivers to fully understand patients. This chapter argues that when it comes to attentiveness in health care, we need to thematize this impossibility as well: the emptiness, the lack of understanding.

**Chapter 8: Discussion**

This concluding chapter reflects on the main findings of this study in relation to the objections outlined in the introduction: to gain a better understanding of attentiveness in the hospital oncology practice, and to find starting points for exploring how attentiveness as we see it can be stimulated and maintained in order to contribute to good care. Then some methodological issues of this study are considered by evaluating the grounded theory, presenting a reflection on the position of the researcher and some ethical considerations. This chapter also describes and reflects upon the main limitations of this study which is also meant to evoke (methodological) discussion and may lead to further research.

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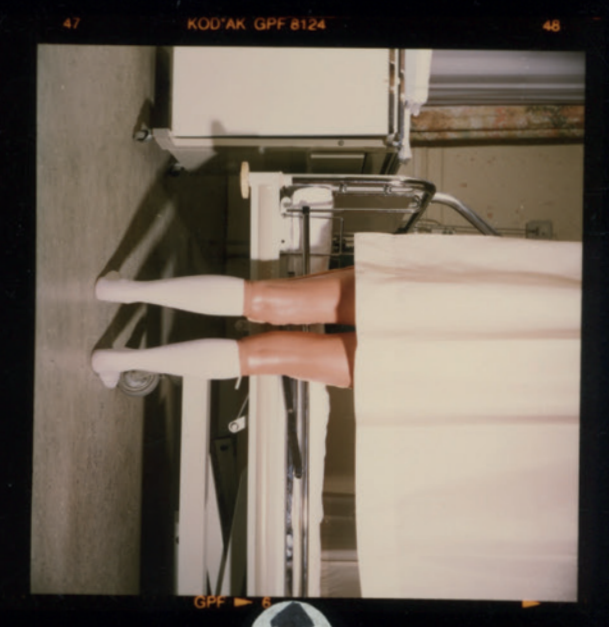
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